Arden&GEM

NHS
Arden and
Greater East Midlands
Commissioning Support Unit

COMMUNITY SERVICES REDESIGN REPORT

Evaluation report- qualitative interviews, face-to-face and online

January 2019

Contents

1. Introduction

As part of the Better Care Together (BCT) programme for Leicester, Leicestershire and Rutland (LLR), engagement activity has been undertaken to hear the views on how a new integrated model of community care changes the experiences of staff, family carers and patients and people who use the service.

In order to support the engagement study, in-depth conversations, to gather insights and experiences were undertaken with the following groups:

- Patient receiving community services (in their own home, in community and acute hospitals, in clinics and other community based settings).
- Family carers
- NHS staff who deliver community services (district nurses, community matrons, Intensive Community Support, community hospital staff, therapists, neuro and stroke service staff and primary care coordinators).
- Domiciliary and care home staff

The conversation explored in detail the following:

"How will a new integrated model of community care change the experiences of staff, family carers and patients and people who use the service?"

The research included:

- Face-to face qualitative interviews with 185 people

They resided in the following areas:

Demographic Area	Number
City	36
East	47
West	31
LLR (didn't provide or did not wish to disclose postcode)	71

As part of this engagement activity demographic data from those taking part was recorded and can be seen in the table below.

Ethnicity:	No	%
Asian or Asian British	25	14
Black or Black British	2	1
Chinese	0	0
Mixed or dual heritage	2	1
White or White British	79	43
Gypsy / Romany / Irish traveller	0	0
Prefer not to say/ didn't disclose	71	38
Other (please specify)	6	3

In addition, the research also included an:

- Online qualitative survey with 66 people

All responses from face to face interviews and online surveys have been individually analysed to identify key themes, similarities, differences and areas for consideration to improve community care services. Furthermore the insights gathered informed the emotional maps within this report and highlighted at what stage different groups felt either supported or not.

This report presents all insights gathered across all groups to allow the three Clinical Commissioning Groups in LLR to understand the current service provision, how individuals feel about the service and explore any suggestions for improvements. The insights will support improved integrated care for patients at home and in local communities.

The feedback received from all interviewees and surveys has been minimally edited, proofed or annotated for the purpose of clarity of response with the reference of any name replaced with xxx.

In addition we have examined 22 existing reports in line with community services from research in LLR representing 4,300 people. The research was undertaken by a range of NHS and voluntary and community organisations.

The business intelligence has been:

- Themed
- Aligned with local and national research
- Emotional maps have been created
- Insights have been created
- High impact principles to improve community services have been created

2. Key themes, similarities and distinct differences across all groups

It was found that many emerging themes were interlinked across the various groups and were pertinent to patients, carers and staff. The research also highlighted the similarities and differences which contribute to delivering effective care to patients. Many themes were linked to communication methods, relationship building with families and staff and challenges within the current community services setting. Further details of the similarities are listed below:

- Family carers, care home staff and domiciliary care staff expressed the need to be more involved in decision making concerning patients.
- Better communication between family carers, staff and internally to include: explanation and advice when required, Appropriate language and use of interpreters when required, To communicate in a timely manner, understanding referral criteria and explaining this to teams, understanding of the services available between the boundary of health and social care and explaining how this effects patients and families and interaction with other services to deliver the best possible care.
- Relationships with other health and social care teams could be improved across all cohorts of people.
- Lack of emotional and physical support for carers and staff and the anxiety and stress this causes and impacts mental health issues.
- Integrated working across teams to improve a number of concerns, including discharge; managing in a crisis and carers seeking further help when required.
- Staff to build good relationships with families to support patients and carers.
- Staff want to be recognised for the work they do whilst ensuring they have ongoing support from their employer and team.
- Staff would like to have more time to care for patients, more training, confidence in abilities and reduce administration.
- Improve IT systems to become more efficient and support all staff.

A comparison across the cohorts indicting any similarities and distinct differences per theme identified.

Theme/Cohort	**Family carers**	**Frontline staff**	**Patients in a community hospital**	**People receiving care in a place they call home**	**Care home/ Domiciliary staff**
Decision making 	Frustrated and anxious with the process	More time and resources to support patients and families and the referral process	Some patients felt supported and listened too and some angry and side lined	Patients feel family are important	Staff wish to involve residents and families with ability to make decisions
Relationship with other services	Mixed feeling	Referral criteria	Critical relationship with discharge team	Mixed feelings some people feel ignored and access to GP is critical	Not always kept up to date by other teams
Supporting loved one physically 	Unsupported and lack of information	Improve relationships to support patients	Advice and support from physiotherapy	Keeping active and building relationships with families, carers and agencies	Coordinating care and having time to care for patients and families
Supporting loved ones emotionally	Unsupported	Lack of skills around emotional support	Importance of physiotherapy in emotional recovery	Keeping busy and socialising	Time to care

Theme/Cohort	**Family carers**	**Frontline staff**	**Patients in a community hospital**	**People receiving care in a place they call home**	**Care home/ Domiciliary staff**
Managing pain	Carers not confident administering painkillers	-	-	-	-
Coordinating loved ones care	Source of stress	Poor coordination causes frustration between services Follow up and review of a care plan	Importance of communication around admission, transport and access	Lack of communication with GP's and district nurse services	Continuity of care across other services through care plans
Discharge 	Not coordinated at point of discharge	Good relationships with patients and families to support a speedy discharge	Knowing what to expect on discharge	-	Effective discharge by working with other services
Managing in a crisis	Feel unsupported in a crisis	-	Reliant on others to support in a crisis	Mixed feeling about managing in a crisis. Falls are a specific concern. Assistive technology and adaptations.	-
Coping with caring/Impact of caring 	Lack of support, want to feel prepared and to know what to expect. Limited time to care for own wellbeing	Workload and time factors	-	Service users worry about the impact on their family	Time constraints effect their time to care

3. Integrated health and care services – the research

The following high level literature review demonstrates that the findings of this report concur with research undertaken by other organisations over the past two years. All references to appendices are indicated by [ ] and are detailed on pages 15 and 16.

A Care Quality Commission (CQC) review of 20 local authority areas [1] found, that while organisations intended to work together, there was fragmentation because services focused on their own goals and planned in isolation to others. The findings reflect many of the challenges highlighted in the LLR surveys, including

- Difficulties accessing GP or appropriate out of hours' services.
- Reduced community services (eg district nursing) resulting in emergency admissions.
- High turnaround of domiciliary care staff.
- Lack of signposting to support services.
- Variation in availability and access to services, in particular when related to transport issues.
- Pressure to discharge patients which can compromise safety, in particular where arrangements need to be made in the community or where there is not appropriate communication.
- Lack of preventive/ self-care services.

Recent research reflects the findings of the LLR surveys

Over the past two years a number of reports have been published which highlight the learning from the Vanguard models and other integrated care systems currently under development. Many of the themes from this learning are reflected in the findings from the LLR surveys, including the importance of:

- Partnership working across NHS organisations and local councils, in particularly important are leadership and a culture of openness and transparency between partners. [2] [3] [4] [5] [6] [1] [7] [8] [9]
- Multi-professional working, creating joint posts across organisations, co-locating teams, and fostering a culture of openness. [5] [10] [11] [12] [13] [14] [15]
- Giving patients and carers a voice in care and decision making, and good communication both between staff and with service users and families. [15] [7] [9]
- Staff training and role development to support integrated working. [6] [10] [7] [13] [8]
- Staff want more time to support their clients. [8]
- Lack of access to up to date patient records and care plans can present issues both for patients and staff, in particular at times of crisis.[16][15] [7]
- When done well integration of health and social care services can enhance patient satisfaction, perceived quality of care and access to services. [17]

In more detail

The findings of the LLR surveys mirror experiences of [3] [4] [15] people, families and front line staff of home care services captured by HealthWatch [8]. They found that while the services enable clients to remain in their own home and retain their independence, experience could be improved by allowing staff more time to familiarise themselves with their client's care plan, there was a lack of the basic skills required for the job, lack of consistency and continuity (in particular around timing of visits) and poor communication.

A CQC report [9] made a series of recommendations to support improvements in care for older people across health and social care including:

- A shared understanding and definition of what integrated care means for the population in their local area.
- Older people should be meaningfully involved in making informed decisions about their care needs and care planning.
- Information and support for older people and their families or carers is available, and this sets out connections between services, and how the people's accessibility needs will be met.
- Development of a set of validated data metrics and outcome measures for integrated care with person-centred outcomes.

Learning from two Vanguards - Dudley [18] and Wakefield [19] demonstrate how closer working across health and social services can produce seamless, coordinated services. Where closer working is in place it can result in:

- Better crisis management and reduction of avoidable admissions.
- Access to a wider range of services.
- A better understanding of roles results in reduced duplication of effort.
- Better support for discharges.
- Increased confidence of care home staff in dealing with adverse events is reflected in the reduced falls ambulance callouts.
- Long Term Conditions (LTCs) and falls management in care homes has improved.
- Increased proactive care management and personalised care planning.
- Closer working with other teams.

NHS Providers have analysed a number of Vanguard models to understand how they have improved the way people experience and interact with health and care services [20]. Their findings also reflect issues flagged up by the LLR surveys. These include:

- Coordinating care around peoples' needs.
- Reducing the need to travel.
- Directing people to the right care, faster.
- Supporting people to manage long-term conditions.
- Tailoring care for people with the greatest needs.
- Making access to urgent care as simple as possible.

- Promoting health and wellbeing among people and communities.
- Supporting carers and
- Working with people to design services that work for them.

A review of learning from the Enhanced Health in Care Homes Vanguards [11] highlights the need for more skilled leadership and equal partnerships, and more clarity around expectations for access to health care, and use of public funds to support training and information systems in independent care homes.

The OPMITAL (A prospective cohort of patients with bone metastases of the long bone) study [21] examined what features of health care provision to care homes were associated with positive outcomes for stakeholders. Again many of the features were also identified by stakeholders in the LLR survey including:

- The importance of time to discuss, plan and review care for residents.
- The central role of GPs.
- The importance of training for all care home staff working with residents and family carers, and
- Recognised referral links with other community and hospital services to support continuity of care and management of acute episodes.

A synthesis of lessons from primary care-led integrated models [6] concludes that integrated care models work well where they are tailored to local needs and constantly evolving. They are dependent on good connections between local people, communities and health-care staff, especially those that allow learning from one another. There should be:

- Opportunities for all the different staff and service users to be involved.
- A shared view of the benefits of working together, with trust for one another and the organisations that they represent.
- Training to support integrated working.

In an analysis of schemes similar to the Multispecialty Community Providers (MCPs) model Sheaff et al [15] conclude that ‘multidisciplinary teams’ are absolutely crucial to the effectiveness of MCPs, and must contain the right professions and organisations, involve patients, and communicate with each other well, and give patients and carers more of a voice. The findings also stress the importance of technology which allows each team to see up to date information about each patient.

Discharge planning

While there is good practice guidance around discharge, such as NHS Improvements trusted assessment schemes [22], delayed discharges are common and often result in poor experience of the health and care system and poorer outcomes. Reports from the National Audit Office (NAO) [23] and CQC [24] highlight the problems of confusion for service users moving between services. Fragmented care makes people uncertain about who is coordinating their care and people are worried about what support will be in place when they return home from hospital.

Research has shown that discharge management with post discharge support, delivered through integrated care services which cross health and/or social care settings can reduce hospital activity [25].

Hospital at Home, a community based service for older people in Exeter to enable appropriate admission avoidance and early supported discharge incorporates a single point of access for referrals, joint geriatrician and community rehabilitation practitioners review for both admission avoidance and early supported discharge, extended weekday and weekend working hours, and an acute hospital ‘step-down’ ward for patients who were no longer acutely unwell. [26].

Physical and emotional support

A study by Ipsos MORI examining the unmet need for social care among older people living in their own homes [27] identified an association between unmet need with poor mental health and anxiety for some people. The study highlights the importance of reliable, accessible services, social contact and involvement in social activities. It identified frustration, boredom and lack of purpose resulting from not being able to do the things people used to do and the daily struggle to meet basic needs which were also found in the LLR survey. Important areas of support came from beyond social care services or the help that their family could provide. This included accessible and affordable or free public transport, being supported in maintaining hobbies or interests or the contacts from them even if they could not participate fully, having control over their housing and the ability to keep it warm and add adaptations when they needed them.

Research by the British Geriatrics Society [28] demonstrates how listening and working with service users living in care homes and their families, involvement of multidisciplinary teams and the voluntary and community sector, and training of care home staff can reduce depression and have positive impact of collaborative, person-centred practice.

Loneliness can have a significant impact on physical and mental health of older people. Work by the Personal Social Services Research Unit [29] identifies befriending, face-to-face and telephone services; participation in social and healthy lifestyle activities; and signposting/ navigation as key interventions to address this issue. Economic evidence is mixed but modelling suggests that signposting/ navigation services can generate a positive return on investment.

Sustained relationships, peer support and confidence building, and encouraging social interactions among stakeholders were some of the “active ingredients” identified by one health and wellness service in North East England. [30].

There is no ‘one size fits all’ intervention to support carers. This is the conclusion of a review of systematic reviews of interventions.[31] Improved outcomes related to mental health, burden and stress, and wellbeing or quality of life. There is potential for effective support in specific groups of carers, such as shared learning, cognitive reframing, meditation, and computer-delivered psychosocial support for carers of people with dementia.

Crisis management

The National Institute for Health and Care Excellence (NICE) has flagged the problems which arise for both patients and staff through lack of access to up to date patient records and care plans presents, in particular at times of crisis. [16]

Wakefield CCG have established three Connecting Care Hubs where health, social care, housing and voluntary and community organisations work side by side helping those people most at risk stay well and out of hospital [19]. Focusing on crisis intervention, the hubs prevent avoidable hospital admissions whilst supporting services to enable people to be discharged from hospital as soon as they are well enough.

Evaluation of the hubs indicate that this form of working was clearly popular among staff having a wider “offer,” faster access to services, and access to more support from Age UK and carers organisations. Staff also thought duplication had been reduced, as their understanding of roles had improved. While experiences reported by carers were mixed, Hub users reported improvements in the co-ordination, responsiveness, and quality of service. They also report that they were more able to cope independently and involved in decision making about their care and support. However, the initiative was not shown to have had any clear impact on use of bed-based services, and therefore no clear overall financial impact

At the other end, Morecambe Bay has demonstrated that a simple video link between a GP surgery and hospital can reduce emergency department visits [32].

Falls, and fear of falls is an important trigger for crises, in particular in people living alone. As part of their falls prevention programme one care home in Hertfordshire tested the Quantitative Timed Up and GO (QTUG) device which generates a falls risk score and determines how a patient responds to interventions [33].The Dudley CCG MCP Falls and Fracture Prevention Service [18] embedded the use of a single point of access.

Use of information technology

Lack of access to up to date patient records and care plans presents issues both for patients and staff [15] in particular at times of crisis [16]. Work in Salford demonstrates how a single integrated record system (Allscripts CareInMotion) across health and social care can support the work of integrated care services [34].

Use of telehealth, such as the automated Florence (Flo) telehealth system which uses SMS text messages to help people manage their condition in their own home has been shown to reduce nurse visits and hospital admissions. [35]. Telecare and

telehealth systems have been used by Calderdale CCG to improve communication between care homes and GPs to improve the quality of care and help to reduce avoidable hospital and GP visits, and reducing falls. [36].
Staff recognition and ongoing support and training Upskilling of staff and supporting staff to adapt to new ways of working are critical. Skills for Health describe workforce development as crucial in successful integration to ensure that health and social care services are delivered in a seamless fashion, shaped around the needs of the patient [37]. Vanguards also report that to staff training and support is important. [10] Evidence on new roles and ways of spanning organisational workforce boundaries to deliver integrated care found an increasing focus on roles which facilitate co-ordination and management of care, development of existing roles to increase the skill-mix and enable the provision of more holistic care.[13]

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Many key themes were highlighted across the various cohorts whilst identifying high impact areas linked directly to each theme. These have been illustrated below and have been detailed in the main report.

Good communication

- Challenges in communicating with families
- Communicating in a timely manner
- To have confidence and trust other teams
- To support and keep up to date with care plans/referrals

Relationships with families

- Important to deliver the right care at the right time
- Staff want to work with patients and families
- Language and cultural barriers
- Patients to understand how staff can help them

IT and administration

- More access to patient records
- Better integration of IT systems
- High levels of admin reducing time with patients
- Use of different IT systems impact care plans

Supported by a team

- Working in silos and not always as a team
- More support from management
- To manage individuals care and wellbeing
- Provide emotional support 24hrs

Partnership working

- Relations with social services can be an issue
- Lack of clarity of available services
- Services are not consistent

Emotional & Physical support

- Mental health, anxiety and loneliness impacting carers, staff and patients
- Carers felt unsupported with little time for themselves
- Carers not comfortable administering painkillers

Discharge

- Services not coordinated
- Discharged too early and without a care plan
- Promises are made that cannot be met

Time factors

- Shifts are not long enough to deliver care
- Reduce the ability to build good relationships with families
- Impact on referrals

Involvement in decision making

- More involvement in care plans
- To be listened to and test suggestions made
- Involve other teams and resources

Training for staff

- Confusion over services and eligibility criteria
- Staff training and role development
- Lack of skills around emotional support
- Guidance of services available to patients

Staff recognition/ Satisfaction in the work I do

- To feel appreciated when supporting patients and families
- Spend more time with patients and families to explain and answer questions

Integrated working

- Staff not sure where to direct queries
- More streamlined services
- Patients can be confused by the roles of different staff

4. Family carers

Emotional map representing the high impact and low impact points of a family carers pathway.

Family Carers

Key: Level of impact

	Involvement in decisions	Relationship with health and social care support	Supporting loved ones	Supporting loved one emotionally	Managing Pain
HIGH IMPACT	*Been a really good service, I get the information I need when I ask*	*District nurses terrific*	*Give good levels of hygiene, mobility and change of catheters*	*Care home supported the whole family after a traumatic time with parents*	*Feel confident in giving the right care*
LOW IMPACT	*Information not shared with other systems and teams*	*Short staffed, Need the right care at the right time*	*Staff not communicating with families*	*Frustration with the lack of care leads to stress*	*Conflicting advice from staff*

	Coordinating loved ones care	Support at hospital discharge	Managing in a crisis	Coping with caring	Impact of caring on life
HIGH IMPACT	*Accommodated our family request*	*Leicester hospital offer fabulous treatment compared to others*	*As a family we are well rehearsed and have confidence to manage in a crisis*		
LOW IMPACT	*Expectation to do something that have not been trained in* *Care from discharge coordinator was not consistent*	*Discharged with no care package*	*Need quicker response from ambulances*	*Not being accepted as a carer to make decisions*	*No time for carers to look after own wellbeing* *More support from GP's is needed*

Family carers

Includes comments taken from both face-to-face interviews and an online survey.

1. Involvement in decisions

Frustrated and left out of the decision making process:
Family carers commented on organisational issues around decision making for their loved ones as well as being frustrated or anxious about the process.

- *Rang 3 weeks ago heard nothing.*
- *Dealing with different agencies.*
- *Not integrated - NHS not joined up. Go through the bureaucracy waste of money. Don't share info systems don't talk.*
- *District nurses come at different time to see them waste of time and money.*
- *Last time it happened reams of paperwork – nothing happened…Frustrating completing the paperwork – not heard.*

How would you like to feel if it happens again?
Carers do not want to have to repeat their loved ones' medical history, and they also want to be able to take a break from caring.

- *Distressing and exhausting to keep repeating story… Looking after carers' wellbeing by not repeating.*
- *It was becoming a full time job, didn't feel I could go on holiday.*

2. Relationship with health and social care support

Relationships with health and social care support teams were mixed:

- *The hospital staff were brilliant… dad's hard work and they really supported us as a family.*
- *District nurse terrific, phoned me up beforehand to ask if ok to come.*
- *Taught me how to pack a wound.*
- *Couldn't have survived without carers.*
- *The care and assistance you do get isn't very good. Need the right care. Uninvolved.*
- *There aren't any.*
- *It is only family who offer meaningful support.*
- *Disrespected and ignored.*
- *Marginalised.*
- *Frustrated - support is limited, extremely variable.*

How would you like to feel if it happens again?
Carers want to feel that all are communicating and working together.

- *Confidence, all singing from the same hymn sheet.*
- *I would have liked a bit more communication.*

3. Supporting loved one physically

Carers felt unsupported, through lack of information or practical help:

- *Leicester Royal Infirmary (LRI) didn't know what was happening; we weren't really told what was going on.*

- *Nurses tell me to get on with it as I had before. "You were carer before, get on with it"'. I walk out room and swear.*
- *Getting to the point- how much longer can I do this? The services are at a standstill… Carer for three years without any support.*
- *Only recently needed help it's been tiring…every time phone rings think it is mum – on edge.*
- *Left to it.*

How would it make you feel if it happens again?
Carers want to understand the progress of their loved ones' condition and to be kept informed.

- *Person deteriorates, healthcare should explain this to you so we understand and know what is expected of us.*
- *Being kept informed.*

4. Supporting loved one emotionally

Unsupported:

- *It is as if it all happened to someone else…Care Home took us all [family] on after a very traumatic 3 months.*
- *Frustration creates more stress "Shut my mouth and carry on".*
- *Part [and] parcel of doing it – mental and physical side.*
- *There was no time we were on our own, we couldn't go on holiday.*
- *Not confident.*
- *Anxious.*

How would you like to feel if it happens again?
Carers want to feel emotionally supported, and that their loved one is receiving an appropriate level of care.

- *Physical and medical support… I feel all on my own.*
- *Husband emotional support couldn't have done it without him.*
- *We know carers coming in and not enough. Mum needs more.*

5. Managing pain

Carers were not comfortable administering painkillers:

- *Dad offered painkillers…don't take them unless desperate.*
- *Tablets give as and when but don't give more than 6.*
- *Having conversation with wife how she is feeling is getting harder.*
- *But dad manages amazingly well.*
- *Just get on with it.*
- *I tend to rely on sourcing information through a variety of means as the local health service seems increasingly ill equipped to even manage a simple enquiry in a timely manner.*
- *Unsupported.*

How would you like to feel if it happens again?
Carers want confidence around managing pain, and that the programme is consistent with their beliefs.

- *More relaxed about things. Confident what I am doing is right.*
- *Some nurses believe in different things I don't believe in.*

6. Co-ordinating loved ones care

Coordinating their loved ones care was a source of stress for carers:

- *I was allocated…a discharge coordinator but it wasn't consistent.*
- *Did feel I had xxx at my head and had to go round home quickly.*
- *Informed in the end stressed on the way.*
- *I need to do something not trained to do.*
- *This won't be sustainable, it is getting more difficult to co-ordinate it.*
- *We know mum can't go home.*
- *No other choice.*

How would you like to feel if it happens again?
Carers want to be confident that the support given will be sufficient, even if they are not available.

- *Confident and in control with the support needed. Biggest worry is if I am ill!*
- *Not unless carers come more often but mum wouldn't accept help.*

7. Support at hospital discharge

Services were not coordinated at the point of discharge:

- *No other support.*
- *Not go to Kettering ever again. Leicester - fabulous treatment.*
- *Discharged with no care package.*
- *Adult social care rang weeks after to say heard dad was at home, they were horrified. It was a failed discharge.*
- *In the dark.*
- *Not confident.*
- *Worried.*
- *Let down.*
- *Inconsistent.*

How would you like to feel if it happens again?
Carers want to be sure that services work together to support a safe, appropriate discharge process.

- *Joined up, safeguard built in.*
- *Dad brought home in pyjamas.*

8. Managing in a crisis

Some carers deal with crises as they arise based on previous experience, while others find it a challenge:

- *We are well rehearsed in our family, even my kids… started at Christmas when mum had a stroke.*

- *Deal with it day by day.*
- *Always been that way.*
- *I get through it. There's no one else to do it.*
- *Try to be as self-reliant as possible as the past and recent experience has shown that the local service continues to fail to offer adequate levels of care and is more interested in playing statistics and wasting resources on meaningless surveys.*
- *I panic and struggled...I froze should have called an ambulance.*
- *Dad said I am worried about mum struggling with mobility... We could have avoided what happened in the end… Tried cleaner but needed more help for mum and dad… was getting difficult.*

How would you like to feel if it happens again?

Carers learn from experience but want more support.

- *I know what to do in touch [time] of major crises – ambulance. Minor crisis – no its impossible.*
- *Bit more confident as this had never happened before.*

9. Coping with caring

While carers did not feel that health services were supporting their needs they "got on with it".

- *I was going back between both [hospitals] and checking house. Had carers to take mum to visit dad in hospital.*
- *You get on with it – would be nice to get more support to take over the caring sometimes.*
- *At some time or other felt all of the above [Stressed, Frustrated, Trapped, Coping, Exhausted, Fulfilled].*
- *Not supported by Adult Social Care (ASC).*
- *Willing to do my best to cope as unable to rely on local services to do what they should.*

10. Impact of caring on life

Caring left carers with little time for themselves, and no time for breaks or holidays:

- *Life is non-existent. Nightmare – but we are together.*
- *People taking over own life – take over our privacy – know this needs to happen – but with dignity.*
- *GP should know what position we are in. We have been on our own for 30 years.*
- *Trapped not able to book a holiday.*
- *Need a break as a carer to go to the pictures.*
- *If want a break for a weeks holiday, can't get wife in a home as needs to be for a month and pay for this plus the holiday.*
- *Life just stops – you have to keep all balls in the air.*
- *Trapped.*
- *Exhausted.*
- *It's a demanding obligation that the failing local health economy does little to ease.*

1. What would give you confidence to receive all your loved ones care at home – medical and social

Carers want confidence that their loved ones are being well looked after through joined up services and a single point of information:

- *Confident is going to be cared for 24 hours a day – going into care home.*
- *Need to have qualified people who understand dementia and interacts with wife.*
- *A support worker.*
- *Evidence that the process would be joined up, that the teams communicate and there would be enough time for each visit and consistency.*
- *More check-ups at GP.*
- *Services being available locally.*
- *Everyone singing from the same hymn sheet.*
- *One point of contact to help coordinate all the different areas of care and a home care book which all visitors complete.*
- *Consistent, not conflicting messages.*
- *Services need to talk to one another.*
- *More information, more support.*
- *To be listened to and understood.*

2. What triggers you to seek further help for your loved one including at evenings and weekends

Carers will seek further help following falls or if they are anxious about a deterioration in the health of their loved one:

- *We have had paramedic out to dad at night…Dad had a fall and head injury.*
- *Blocked catheters, falls any emergency.*
- *Decline in health and falls.*
- *His pain level and mental health.*
- *Concerned.*
- *Nothing. Unless there was a medical emergency.*
- *An emergency. Nothing else will get a response.*
- *Pain and illness not being managed.*
- *A deterioration in health would 'trigger' a need to contact health services and or a request for support or assessment from Adult Social Care.*
- *I only seek help if they have increasing and acute health needs eg exacerbation of respiratory problems.*

3. When seeking further help what is your experience of accessing care

Experience of further help tended to be poor:

- *Ok when know where to go.*
- *Go through rigmarole to gain nothing.*
- *GPs don't always understand.*
- *Care is not available.*
- *Individually great but services are overstretched.*
- *Passed from pillar to post - confusing who does what.*
- *Really bad.*
- *Endless phone calls.*
- *Poor.*

- *Often difficult to get through to GP reception. Slow, difficult and if it is not a serious emergency unresponsive.*
- *Not clear where to get help and services don't seem to talk to one another*
- *Disgracefully poor.*

4. How is receiving care at home different from similar care your loved one has received in hospital (if applicable)

- *Apart from fact it was impossible – it was piece of mind for us.*
- *I have worked with people where the full package at home works. But for us and others it is waiting for the next crisis to happen if they stay at home.*
- *Went into acute…everyone on board…no problem. Kettering dreadful…in hospital communication terrible in Ashton Ward.*
- *3 months waiting for incontinence pads. Took a month to get an appointment and not being seen till December.*

5. What things matter to you about accessing health and care for your loved one that help you cope?

Carers want support services for their loved one to be reliable and appropriate, and to be prepared and kept involved. Poor experiences of the discharge process caused concern:

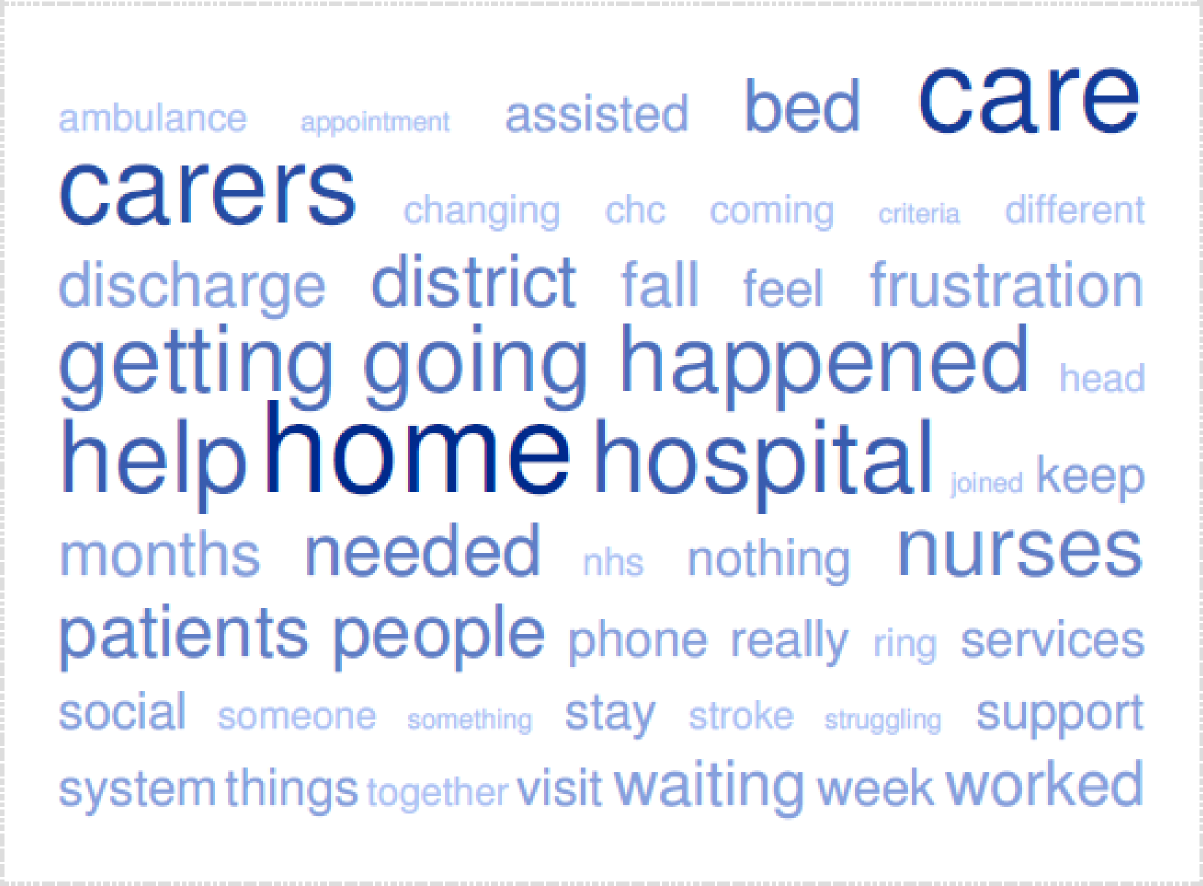
- *No long term re-habs no where to send… they end up staying in hospital.*
- *Went backwards on new District Nurses system… Nothing went onto new system*
- *– difficult to get an appointment.*
- *District nurses turn up randomly - don't say they are turning up. Have to wait in all day for them. Don't communicate when they are coming back.*
- *People came in morning to wash her but wouldn't help me get her downstairs, stood and watched me get her down on her bottom.*
- *Lack of communication between services/carers/GP.*
- *Availability of services.*
- *What would matter most would be a fully funded system with properly supported staff working in it.*
- *Continuity of care so that we don't have to explain complex histories over and over.*

Carers want to feel prepared and know what to expect:

- *What to expect.*
- *Left hand doesn't know what right hand is doing.*
- *Made to feel useless and stupid.*
- *Things changed overnight.*
- *I have had training in my role for NHS so know a little bit. It must be hard for people who know nothing.*
- *One time he said that I was fit to look after her and now not seen anybody, don't get help now.*
- *No one helps you to know what assistance you can get.*
- *A designated point of contact for all care coordinated.*
- *Clear information and timescales. Not having to constantly chase for what is happening.*
- *Recognising the need to keep carers/families informed.*

Carers were not happy with the discharge process:

- *Discharge – I didn't feel we were working together.*
- *Discharge from hospital, don't inform carer of changes of meds and waiting for equipment to arrive and patients sent home.*
- *Patients discharged too early.*
- *On way out of hospital yesterday told my husband being discharged next day. I have refused him to come home as he can't go to the toilet on his own.*



(Key words used across all family carers questions)

A summary of themes highlighted by carers:

- Family carers want services which are reliable and appropriate to their situation and allow them to support their loved one. However they report difficulties in getting the help they needed and frustration around the processes, including decision making and discharge process. Getting further help at times of crisis were a particular challenge for some.
- Carers reported mixed relationships with services and staff. They did not always receive consistent information and were not involved and kept informed.
- The caring role resulted in emotional stress for carers, such that they did not feel that they could take holidays or breaks.
- Particular areas of concern were falls, getting help when their loved ones’ health deteriorates, administering painkillers.

5. Frontline staff

Emotional map representing the high impact and low impact points for frontline staff.

Frontline Staff

Key: Level of impact

HIGH IMPACT
LOW IMPACT

Relationship with person and family
- High impact: *Easy to communicate with anyone*
- Low impact: *There is never enough time to assess*

Involving and communicating with person and family
- High impact: *I am confident with patients*
- Low impact: *Difficult – don't always understand their condition or my role*

Relationship with other health and social care staff
- High impact: *Wards and colleagues trust my opinions*
- Low impact: *Communication can be a problem*

Involving person in decision about their care
- High impact: *Patients are involved from the day they are assessed*
- Low impact: *Family decisions are not always the patients decisions*

Decisions about care and referral
- High impact: *Nurses and Management are approachable to discuss patient needs*
- Low impact: *Need clearer pathways*

Accessing other care, reviewing and making a referral
- High impact: *Some can refer direct via system one*
- Low impact: *Challenges in liaising with agencies and social workers within a given time*

Coordinating and providing physical and emotional support
- High impact: *Provide signposting and support to families*
- Low impact: *Lack of time and resources to support this*

Relationship and working with other services
- High impact: *Good relationship with therapists, nurses and GP's.*
- Low impact: *Improve relationships further by communicating and having an integrated approach*

Follow up and review of a care plan
- High impact: *We commission and review regularly*
- Low impact: *Very time consuming and not always kept up to date*

Employer and team support
- High impact: *Management are very approachable and supportive of the team*
- Low impact: *Feels like us and them when working with social care services*

Frontline staff

Includes comments taken from both face-to-face interviews and an online survey.

1. Relationship with person and family – how do you feel?

Staff stress the importance of building good relationships with their patients and families, and in particular to support the discharge process.

Relationships:
Good relationships with the patient and family are important. This can be challenging where the family are demanding or have preconceived ideas about the available care.

- *I want to help them and make them feel better. It makes me happy when someone is happy here.*
- *Families have their own thoughts about how the care is going to go and don't understand the eligibility criteria.*
- *Need to have good relationship with the family (but) hard to speak to all families.*
- *Important to have time to make contact with service users/family.*
- *Some easy and co-operative some think intrusive.*
- *Some challenging families… can have family members who all want to be the spokesperson.*
- *Have some challenging families…Try to undo any pre-conceived ideas – can add to pressure right at the beginning.*
- *Having rapport with them [patient]. It's very important.*
- *Easy when time to do holistic assessment … Can be difficult as on skeleton staff.*
- *Every patient is different and family different.*
- *There is never enough time to assess.*
- *It is families that need support.*
- *Patient is never any bother, it is the family, patient's relatives want to know what is going on*
- *[Relationship] Makes a huge difference to the impact of intervention.*
- *Rapport with patients is most important.*
- *Get feedback from relatives and get to know patient before came in for baseline. Seen as being a busybody.*
- *On the whole can be positive relationship, relationships can be hard some challenging families out there.*
- *Some families want to interact some are not willing.*
- *Not close – you don't get the time.*
- *Patient expectations are high – you explain the service isn't like that anymore.*
- *Lacked continuity – don't see same people regularly – can't do job properly – need to build rapport.*
- *Important - to communicate about family members need.*
- *Difficult – don't always understand their condition or my role.*

Discharge:
A good relationship with patient and family is important to support speedy and safe discharge.

- *Need to have good relationship with the family.*
- *Families can get in the way of discharge – not necessarily patients.*
- *Don’t get patients out if don’t collaborate with the families, can’t discharge safely.*
- *Meet with negativity from the family who don’t want to support the patient being at home.*

How would you like to feel if it happens again?

Relationship with service user and family:
Staff want to support and work with patients and families.

- *Some people don’t like to hear what you are saying.*
- *Keeping people informed.*
- *We have to work well with relatives.*
- *People need to know people care.*
- *Nicer for patients to understand what we can prioritise.*

Workload/ time factors:
Staff are aware of the time and workload pressures which reduce their ability to develop a good relationship with patients and families. Sometimes this impinges their personal time.

- *A caseload that allows you to have enough time to talk to people, undertake assessments and provide right level of support required.*
- *Time is the biggest factor.*
- *Too much paperwork.*
- *Don’t always have enough time to more than just do the care.*
- *Nice to have more time to explain things and get rapport with patients/relatives.*
- *Have appropriate level of staffing… it’s never happened.*
- *Time and resources are stretched.*
- *It’s very reactive rather than proactive.*
- *It’s all about time again.*
- *Families think they are the only people we have to care about. I have my own commitments and can’t work late.*
- *Sometimes want more time when dealing through difficult issues. I make time often my own.*

Access to patient history/records:
Staff would like access to patient records so that families do not have to repeat their story.

- *Shared documentation and UHL have access to that. It works now as we can talk to families but they do have to repeat their story.*

Service integration:
Staff do not always know where to direct queries.

- *Overlap due to structure which is confused – doesn’t always know where to direct my queries and it’s not clear who is doing what.*

Discharge process:

Sometimes promises are made around discharge which cannot be kept.

- *Ward staff make promises to families while they are in hospital about the discharge plan without consultation with the community support team.*

2. Involving and communicating with person and family:

Staff highlight the importance and challenges of involving and communicating with patients and families.

Communicating can be challenging initially, in particular when the family and patient disagree.

- *I am nervous in the end it is fine… Everyone is nervous at first.*
- *It is taking a bit of time to get to know the resident and family and how they want things done, but after finding out it is good.*
- *There is no easy way to have End of Life (EOL) conversation it's how families receive information – working in team – supported by nurses, social services to be able to have difficult conversations.*
- *Its rapport with patient/family from initial assessment…. Patients open up more than they first did.*
- *Sometimes challenge for those that can't communicate verbally. They get frustrated and so do we. Confident most of the time.*
- *You do your best to do that.*
- *Some patients have the capacity to make their own decisions but can be difficult if the family disagree with decision even if they have the capacity.*
- *Families can take over and cause most issues – more than service user.*
- *With family we always try. The patients sometimes don't like things. They say family want you to do this. We explain it is what the patient wants.*
- *Getting to know patients and what their needs are – can be challenging – lots going on behind the scene.*
- *Families can be challenging, we explain that the patient has capacity but we can't force the patient or go against the patient's wishes.*
- *Patient is the priority but it is a balance.*
- *Do find general public don't respect this profession like they used to.*
- *With training received feel confident.*

Staff stress the importance of getting to know each family:

- *It depends on patient family…Everyone needs to be treated as individual.*
- *Family have an agenda and we sometimes can't provide what they need.*
- *Some families like to be involved others don't.*
- *It is a bit of investigation before you can care for one person.*
- *It's a collaborative approach.*
- *I try really hard to build good relationship with family. If that is right it all falls into place.*
- *Not seeing same patients don't know family… This makes us frustrated as not doing jobs properly and leads to low morale.*

There are sometimes language or culture barriers to good relationships:

- *Language barriers – can be lengthy to get interpreters, family members and ward staff together.*
- *Challenging is part of the job when working in public eye, different cultures/social issues.*
- *Some families don't want or can't be involved if they don't live close… but different cultures act differently.*

How would you like to feel if it happens again?
Specific issues raised by staff include spending more time with the patient, more streamlined services and better access to translation services. Staff want to be recognised for the job they do and to feel that they do a good job.

Staff stress the importance of developing a good relationship with service users and family, and would like to be able to take more time to do this.

- *Patient wants something different to families it's their life.*
- *Family agree and patients doesn't agree as might need to pay for it and patients worried about inheritance.*
- *Talking to relatives/patients explaining why it's important we do things the way we do.*
- *We know people here. Patients more willing to open up and tell us things.*
- *Smaller teams few key people here and know what's happening with patients*
- *To have time to respond.*
- *People don't know the local area when making appointments. We used to have own areas previously… you have no continuity.*
- *More time for the first time – 5-10 mins would make a lot of difference… People just want a little time.*

More streamlined services would help both staff and families:

- *It would be great if the system was easier to understand and less fragmented for patients and family.*
- *Dispute to us and other discharge services …What we say we offer is different to what we do offer…I am a big believer that colleagues spend time on other services to understand what is on offer…All have different processes.*
- *It's getting families to understand what we can offer.*
- *All GPs on SystmOne as would make it easier to access information.*
- *Provision of services around social care done quickly rather than multiple calls to different people.*

Staff want to be recognised for the job they do and to feel that they do a good job:

- *Good if everyone agrees and the outcome is successful. Devalued if don't agree with assessment.*
- *Some families think we are just carers need to be more informed in who we are.*
- *Always improve – reflecting on what goes well and improving what hasn't gone well.*

Services which staff feel would help patients include interpreters and patient transport:

- *Long process for getting interpreters.*
- *If we could provide patient transport.*

3. Relationship with other health and social care staff

Building good relationships with other staff is very important to ensure high quality support for patients. However this can be challenging when other teams do not communicate clearly or in a timely manner, or when referral criteria are not clear or understood, in particular with Social Services. There is a lack of clarity around available services, in particular on the boundary between health and social care. Staff are aware that promises are not always met.

Good communication:

- *If they are ones I don't know, I don't know how to talk to them.*
- *You need to be professional and up to date if you have nurses coming.*
- *We got a good interface with community team and our goal was the same.*
- *Relationship is strained because of the system.*
- *Varies from case to case – have to put effort into interactions.*
- *Great integration – feel united with other teams and discharge team – good relationship and communications.*
- *I am proud of the links that I have on my wards and with my colleagues.*
- *Amazing lady who comes to ward round meetings is a mind of information.*
- *It's improving. Homecare Assessment and Reablement Team (HART) carers come to board round each week. A lot of work around liaising and patients we share.*

Challenges when other teams do not communicate clearly or in a timely manner, when referral criteria are not clear or understood:

- *I left a message but I needed an instant response.*
- *GPs frustrating when trying to get info.*
- *No call back [from GP] so I don't know what to do – need a plan.*
- *When trying to get in touch with people in other services difficult to know who is involved with the patient, this can be challenging.*
- *Some train them well others it is disgraceful…I know they don't get paid very much. But it is not the point.*
- *Sometimes niggles between team. Sometimes problems with team… Sometimes HART team can get stroppy. Their criteria is tighter now.*
- *Sometimes they came to us in a crisis and whether it is relevant for Intensive Community Support (ICS) or not we deal with it.*
- *Putting certain goals in place want them to be walking with a frame in two weeks, they will big things up to get them out of the acute.*
- *No mutual respect over the phone asking them to come in as need help it's a battle.*
- *Confidence in ICS has deteriorated in last six months.*
- *Role of primary care co-ordinator they should be referring. Nurse often just refers and doesn't know patient. Quality of referrals from acute needs to be better – more realistic and honest.*
- *Sometimes communication can be a problem.*
- *Social care/Advanced Nurse Practitioners (ANP's)/Consultants don't talk to Health Care Assistants (HCA's).*
- *Difficult to communicate with GPs as don't know them – have to go through reception – GP rings back so not with patient – social services can't get through to – on hold.*
- *Not proactive used to have monthly meeting with District Nurses/Macmillan it stopped.*

Relations with Social Services can be a particular issue:

- *With regard to social services and getting care agreed is a slow process…we often end up providing care before they come in.*
- *Social services - relationship broken down used to have support workers ahead of multidisciplinary team (MDT) meetings it now hit and miss.*
- *Can take weeks to get named social worker.*
- *Social care – more face to face contact wouldn't get attitude, name people know how you work, respecting what asking. System would be more efficient.*
- *We have half hour window – they visited social care early and we missed them – we explained our situation.*
- *Carers from social services finding them and tapping into can be difficult.*
- *When had key person it was a lot better it was great now just phone a number told not been allocated yet, question everything you want.*
- *The ambiguity arises when you have health and care colleagues where you get services offer from local authority to local authority. It's always a challenge.*
- *Social services a nightmare.*
- *Service pressures for LPT/ Social Services is difficult to meet up.*

There is a lack of clarity around available services in particular on the boundary between health and social care. Staff are aware that promises are not always met:

- *I think sometimes the boundaries are so close – they say it is a health need when they do need social care.*
- *The doctor on ward will promise earth on what is offered in the community. You build up families hopes and they are led to believe this service is on offer and it isn't. There is a need for better information on what is offered.*
- *It's just getting them to understand what we can offer i.e. assessment beds – not offered by the county.*
- *Relationship to community services recent changes week to week.*
- *Quality of referrals from acute needs to be better – more realistic and honest.*
- *Social care – more face to face contact wouldn't get attitude… System would be more efficient.*
- *Its healthy positive knowing who to go for the right info through building relationship know who to go to.*
- *Patients happy with [reablement] but when have to pay we cancel the help so go into hospital*
- *Social services told hospital staff not to get involved with finances. But they won't help if patients are self-funders.*

How would you like to feel if it happens again?

Staff would like to understand what is offered by other services, including more direct face-to-face contact and visits. They want to work together to reduce workload and repetition and suggest that improvements to IT systems (in particular SystmOne) would help.

Relationships with other services:

- *Pack of information of services of what they do… Nothing in writing to say what they do… I went on a training day as an observer with district nurses – it helped me to go out for one day with them.*
- *Weekly visit to ward rather than just doing stuff on the phone.*
- *With Integrated Community Response Service (ICRS), it depends who you talk to on phone on what they will do.*
- *More direct contact and know people in hospital setting.*
- *We are employed to areas and need an appreciation of each other's jobs.*
- *It's about finding time to build relationships with new colleagues.*
- *GPs to be more open with patients and see them when they are poorly.*
- *At the moment we are signposted shouldn't require NHS action as not a healthcare action have to get involved as social care not managed properly.*
- *Know District Nurses has improved using hubs and dedicated nurses. Always someone clinical at hub.*
- *When they come we know they are going to be informed…We know which patients are on the list.*
- *Trusted assessment, respecting others opinions rather than assessing again.*
- *Hard when someone else takes it on and it goes back to how it was before I helped make it better.*

Improvements to IT systems would help:

- *Having access to computer systems i.e. nerve centre would be really beneficial.*
- *Better systems so can communicate over tasks, IT related.*
- *Set up link to services i.e. SystmOne can see what has been happening in different services.*
- *Easier to contact via system one or direct phone line.*
- *Better if social care all on one system, mental health on SystemOne and joined up approach.*

There are issues around lack of time and workload:

- *NHS is very busy and referrals take so long.*
- *Staffing levels to accept and work together more.*

4. Involving person in decision about their care

Staff consider care to be a "joint venture" and therefore involving patients in decision making is very important. However this can be difficult if patients do not have capacity, do not want to get involved in the discussion, or where family does not support the patients' decision. It is important to help patients understand the different services, and staff roles across different services, as this can cause confusion.

Staff try to involve patients where they have capacity:

- *We already know who has capacity and who hasn't, we always give them the chance.*
- *But sometimes [patients] want to be told what to do. If you give them options it causes confusion, it is breaking culture to give patients permission to decide.*
- *Our aim is that where a person has capacity it is always their decision.*

- *Patients are always involved unless they did not have capacity to talk about the issues they have raised.*
- *[Patients] will not have enough engagement if they are not involved – part of the consultation process.*
- *I explain that it is best for them and get them involved.*
- *Make sure you tell them what you are doing.*
- *It seems quite refreshing when people make decisions based on what matters to them most.*
- *Ultimately you having difficult conversations with vulnerable people at critical times in their life, our priority is always service users first.*
- *Always ask the patients how she wants things done.*
- *We don't take unilateral decisions it is a joint venture.*
- *If they do not have capacity it is difficult. As much as they can be involved, they will be.*
- *Recently more driven approach to health care, self-care, prevention reviewed patient info to improve shared care.*
- *It's about what patients want to achieve rather than what we want – if not on board won't achieve their goals.*
- *Once know the patient make decision of care easily.*
- *Make sure you tell them what you are doing. Especially if they have dementia you have to tell them.*
- *Hardest bit to get their involvement to make a decision.*

It is not always easy to involve patients when they don't listen, or where family does not support the patients' decision:

- *Need patients to listen.*
- *The family needs to be up- to- date with anything, if not it is not good communication with everyone if we can't deal with patient.*
- *[Patients] don't take responsibility. Family say you are NHS and you should be doing it.*
- *Family have far too much influence. Even when well-meaning the patient sometimes doesn't get a say.*
- *Need to speak to them alone without family members.*

Patients can be confused around the roles of different staff in particular when transitioning across services. It is important that services work together:

- *We have to explain it is only a 10 day service, they say they want us to carry on with care. They can't differentiate us from carers or district nurses. That is difficult, we try to explain what our role is but they get confused.*
- *Because we have reablement care it is free for a few weeks. When they have to pay that is another matter.*
- *We make sure that all the regular visits are properly staffed and managed. Can be challenging because of working with different teams.*

How would you like to feel if it happens again?

Staff want time and resources to support the service user/family to make decisions:

- *Tapping into the carer.*
- *Don't think we provide enough time to sit with patient and explain their options… people get pushed into doing something they didn't want to do to keep the peace.*
- *Giving realistic expectations on what community services can deliver.*

- *Left patient with something to read after we have gone.*
- *Interpreting service to support staff when visiting patients where English is not their first language.*
- *Making care plans more personalised – they are to be adapted.*
- *It's easy to say this can't be done due to team capacity. Need to get info and engage with patients.*
- *It is about capability, it is always about skills.*
- *Have info leaflets to give out and document that tell them when the next person goes in.*
- *Having funding for services to do what we want quickly.*
- *Felt more able to tap into other services for support and beneficial for the patient.*

5. Decisions about care and referral:

There is significant frustration around the referral process, including inappropriate referrals, cumbersome processes or a lack of information about other services. SystmOne is generally considered to be making the process easier.

Inappropriate referrals and cumbersome referral processes:

- *We have to go to GP for other referrals we have to remind them. Not always feel good to remind them, they sometimes lose our faxes and we have to call them again. It is frustrating and waste of time.*
- *Sometimes we get referrals from wards not appropriate – waste of time.*
- *Call before the patient is ready for discharge. Feels like a waste of time.*
- *It usually takes a while particularly social services.*
- *Referring to social services needs to be easier.*
- *All assessments should be done before the referrals are made – would reduce inappropriate referrals.*
- *Sometimes [the] difficulties with referrals is our service getting right info from acute and primary.*
- *Continuing Health Care (CHC) – Fast track not fast, not worth paper written on. Makes rules up as go along, not consistent.*
- *Spend more time on admin than with the patient.*
- *Don't know whose benefit the help to live at home form (help to live at home form is 14 pages and is horrible, just a tick box).*

There can be confusion over the possible pathways and care packages and what they can do:

- *Clearer pathways. One of my jobs is to educate people on choice of pathways …CHC is timely and complicated. Trying to explain that to relatives is frustrating.*
- *Happy to make referral. As long as I 100% know what is offered.*
- *Decisions are made by Manager which can cause some conflict if I have a different view to the manager… Health are more risk averse and this can cause conflicts.*
- *Sometimes we get referrals from wards not appropriate – waste of time. Can be a battle and frustrating for the service user.*
- *The hospital staff will not necessarily listen to the referrals options that I suggest… Checklists are being done too early… patients are discharged into the community too soon.*
- *Reablement don't get a full picture of why [patients] are in the service. Not an awareness of other agencies of the service, expectations are unrealistic.*
- *Patients referred to come to therapy and don't know why.*

- *GP's /hospital staff in acute have an unrealistic view of what is able to be provided in the community.*
- *Patients say that they are not happy as they have been given the wrong info in the first place.*
- *Unfortunately referral pathways are not always clear. Services change and no info.*
- *Both health and social care being internal makes it easier than other areas… In Rutland easier because it is an integrated service.*
- *We are quite good at discussing services about patients at MDT meetings.*

IT systems – SystmOne:

- *Referrals are tricky as keep changing so can spend an hour looking for right form on system one.*
- *I would prefer fluid IT system between two SystmOne for health plus other system for social care working on improving this so hope this will change soon.*
- *In Rutland it is easier because it is an integrated service. SystmOne works for me in that respect.*
- *Good practice on SystmOne so can access info.*
- *Electronic referrals are easy.*
- *Like electronic referral. SystmOne massive change made big leaps to getting close.*

How would you like to feel if it happens again?

Staff suggest that closer working between services, with appropriate IT support, would improve the referral process.

- *Meetings with University Hospitals of Leicester (UHL) to discuss what reablement is about and what the service can be provided. Patients then know what to expect from the service and what can be realistically provided.*
- *More around mutual understanding … have clearer authorisation changes making this easier.*
- *More robust standard operating procedure where teams accept triaged patients.*
- *Meet other therapists to go through template to get consistency so all singing off same hymn sheet.*
- *All assessments should be done before the referrals are made – would reduce inappropriate referrals.*
- *Don't understand what get from form, tick box exercise and patients don't fit need to add extra info - not met such a god awful form in my life.*
- *If Social Services it is our MDT and that is straight forward – Therapeutic Drug Monitoring (TDM's) are more difficult… If you refer to them we need acknowledgement… we don't know what is going on.*
- *Prefer fluid IT system between two SystmOne for health plus other system for social care*
- *All on SystmOne – just an electronic form on SystmOne.*

6. Accessing other care, reviewing and making a referral

Understanding what other services are available, eligibility and the referral process can be problematic for staff.

There is confusion over what services are available or eligibility:

- *Massive problem ambiguity of what is on offer in community.*
- *Package of care – can be long waits to get patients home.*
- *Difficult when there are issues and they don't meet the criteria.*
- *Patient doesn't get signposted the right services as stress in system.*

The review and referral process can be problematic:

- *As admin, trying to do everything we're like 'piggy in the middle'… it's frustrating and upsetting.*
- *If we are referring to social service online. It is a most difficult form; it used to be a phone call. It was quite straightforward. Now it is like war and peace.*
- *Sometimes difficult can't refer directly have to go through 3rd party. Trusted assessor can make clinical decision around assessment.*
- *Systems not talking to each other.*
- *It is the paperwork. It is not a 5 minute job. A lot of the forms can be bounced back if they are wrong.*
- *Social Services is hard work – difficult to get hold of them.*
- *CHC is a minefield for staff as well as patients.*
- *Some services are time consuming to refer to eg Social Care Occupational Therapist.*
- *Can be difficult to access other services.*

How would you like to feel if it happens again?

Staff would like knowledge about other services going forward, with clearer care pathways and referral systems and processes.

- *Would like more knowledge about what current services are available.*
- *Lots of people/ patients say no, we don't have any other options.*
- *Our entire service is slowed down waiting for other services, and there aren't enough community providers to cope… systems and processes are fundamental issue… Why can't I refer directly.*
- *Sometimes waiting a long time for them to get back to us – it blocks the bed.*
- *Know when to ask for help.*
- *Patients can end up in two care pathways, one for social and care – need pooled staff and budgets.*
- *Everyone work off same page or goal to get patients out in a timely manner.*
- *Simpler referral system.*
- *Systems that talk to each other.*
- *All on same system.*
- *Patients don't always go to appropriate service.*
- *CHC process simplified.*
- *All being on same system – not being frightened to pick the phone up and get used to who people are.*

Again there is confusion over what services are available or eligibility:

- *Massive problem ambiguity of what is on offer in community.*
- *Package of care – can be long waits to get patients home.*
- *Difficult when there are issues and they don't meet the criteria.*
- *Patient doesn't get signposted the right services as stress in system.*

7. Co-ordinating and providing physical and emotional support

Providing physical and emotional support can be challenging depending on the time and external resources available and individual confidence where staff feel they do not have appropriate skills. However it can also be a positive aspect of the work. Poor coordination between services causes frustration for staff and service users.

There can be challenges around providing emotional support partly through lack of time, but also confidence and resources:

- *It is difficult to send someone home who isn't ready… If patient is worried I use Royal Voluntary Service (RVS) and we get good feedback. They will come to the ward – it gives you confidence.*
- *I would like to think all of my professional group make time. But actually there isn't enough time, we don't have the resources.*
- *Less confident on the emotional services out there.*
- *The emotional side can be difficult People disclose all sorts – its knowing the safeguarding threshold.*
- *Lots of frustrated families.*
- *That can be difficult. It depends on the nurse; it is the fluffy bunny stuff. I am more practice – other will be fluffy bunny others are good at both.*
- *You talk to colleagues and get ideas. I think we should all be based together not split up all over the place.*
- *I think most of my job is more social and emotional than medical.*
- *Got emotional support – got Mental Health facilitator help in the practice.*
- *If see patient/ family struggling, I will chat and give support, report back to someone in higher position.*
- *Feel that I have the support of the team.*
- *It can be challenging supporting people at end of life don't know how far to go and what can be provided.*
- *It is tough prioritising visits… Trying to keep on top of paperwork. It all comes down to time. Haven't got time to talk to people.*
- *All these lovely people been identified nurses going in but no time to chat.*
- *Emotional support very difficult can refer for counselling…but wait for 6 -8 weeks to see someone. We do what we can but we are limited by time.*

Some staff indicated a lack of skills around emotional support:

- *If [service users] open up around emotional issues this can be difficult to support as don't have skills or remit.*

- *We ask for training to learn how to interact with the patients social services get someone to assess them before they get the package of care.*
- *Mental health patients may have physical problem but they will also have emotional issues so we need more training in this.*

Patient support can be a positive aspect of the work for staff:

- *I like that I can spend time with them. Trying to see how I can help them.*
- *Pretty good we give massive emotional support. I think most of my job is more social and emotional than medical.*
- *Can be emotionally draining but it is nice when you see that it's worked.*

Poor coordination between services:

- *Service Users get angry and so do the family.*
- *When you need input/ agreement and no one is available it's frustrating.*
- *I know District Nurse team are not allowed to keep palliative patients on caseload for emotional support. If not physically changing dressing, can't see them.*

How would you like to feel if it happens again?

Staff would like more guidance, training and time to give patients support, and more information about what is available to help them.

More guidance, training and time to give patients support:

- *If a patient needs it we could spend 10 minutes to half an hour to chat with them.*
- *Booked appointments 10 minutes can't provide good emotional support structure as don't have time to do it.*
- *Induction/training on mental health - E-learn doesn't help should be someone with experience to take through case studies – reflective learning.*
- *Having support from team.*
- *Some kind of guidelines.*
- *Management availability – when you need input/agreement and no one is available it's frustrating. Reducing management has made things difficult.*
- *Health and wellbeing included in Personal Development Review (PDR) & supervision.*
- *If patients categorised geography patients/staff covering a smaller area cut down on amount of time in a car.*
- *See people with dementia – diagnosis can take a long time and is generic - service users get angry and so do the family.*

Staff want more information about what is currently available:

- *Provide more services in community.*
- *Would like more knowledge of emotional services available - such as an online directory of services.*
- *Comprehensive list for mental health [services].*

8. Relationship and working with other services

Good working relationship between all services is clearly important to staff, and frustrating when not in place. Relationships between services are helped where individuals know each other. One area of improvement highlighted was involvement of different teams in decision making, so that each team understand the capability of the others.

Relationships between services vary from positive, variable to poor:

- *I have a discharge booklet on what I refer to district nurses for… Includes contact details so I have confidence.*
- *Good working relationship with integrated team, therapists, GP's.*
- *As a whole GPs are very good when we bring things to their attention.*
- *Depends who it is.*
- *You need to be up-to-date and informed and have information to pass over to other services.*
- *Updates from different services any changes can/ can't deliver.*
- *Single point of access – staff need more training to understand the referral and get more info on what is required for the patient.*
- *Communication [between services] can be poor.*
- *More shared systems would help relationship.*
- *A lot of pressure on every service. They focus on job rather than relationships with other teams.*
- *NHS – not always joined up if get problem with delivery don't get narrative as to why there is a problem.*
- *Can be challenging as all protecting our own backs play patient ping pong as protecting our own capacity.*
- *Variable depending on individual there is complete disconnect.*
- *Acute therapists can be seen to look at things with rose tinted glasses.*
- *I documented his response that he wouldn't come every two weeks. I was only doing my job.*
- *GP could come at a more convenient time.*
- *It can be strained and difficult with social care at times. Generally relationship overall is good. Open dialogue. More shared systems would help relationship.*

Relationships between services are helped where individuals know each other:

- *Have had joint meeting and shared ideas. That helps with relationships.*
- *Not speaking to the same person is challenging.*
- *Got to know the other teams from previous job which has made the transition easier.*
- *Can be frustrating and challenging – I know a lot of teams as been there a long time and have built relationships across GPs, Nurses, Local Environment Services, Police.*
- *Don't know them, makes it harder to run something past them – have to go through referral process and don't know if referring to the right service.*
- *Don't know anybody used to have a regular nurse. Don't know colleagues at all done at the end of the phone.*
- *Know physio at Coalville clinic. They will feedback on patient progress.*

How would you like to feel if it happens again?

Responses confirm the importance of good working relationships with other teams, where teams work well together and trust each other to do their job.

- *You need to be up to date and informed and have information to pass over to other services.*
- *A greater understanding of what is available from each service.*
- *Stopped referring to ICS – no longer have a bridging team.*

- *Would be good if we all work in the same place (Discharge Teams) – one centralised hub would be best scenario.*
- *Trusted assessment health provided or social care then should trust the assessment and not be done again.*
- *Updates from different services any changes can/can't deliver.*
- *Building relationships open door policy.*
- *Better integrated working within Leicestershire Partnership Trust (LPT).*
- *Lot of staff have worked in other services so relationships are already established which makes it easier.*
- *Get information about activity.*
- *Pick up phone speak to someone meet colleagues who provide service sub-localities meetings were good, these have stopped.*
- *Know staff in the services to give point of contact. I believe co-ordination of care as [at] present there is none.*
- *Have to beg and prove need bed. Don't make me accountable if staff in [the] office decide patient can't have bed.*

9. Follow up and review of a care plan

Care plans are important to good patient care, but can take a lot of time. Where care plans are shared across different teams there are issues including duplication of effort and information governance/ consent.

Care plans are considered useful but the process could be improved:

- *Very helpful and good for me.*
- *Fine no concerns.*
- *We can be involved in care plans we quickly see changes.*
- *When social services or care company contact us we pass information on. What the patients want and doesn't want, tell truth about person so they go in open minded.*
- *Plan is updated when everything changes. The nurses go out and review. The patients then get consistency.*
- *Processes in place to review care plans before discharge. We have outcome measures for plans to measure how effective the service is.*
- *Care plans keep changing fairly good idea, patients like something in-house.*
- *It is a bit haphazard. We plan reviews – they wouldn't necessarily happen at the time and difficult to co-ordinate, regular planned meetings to improve.*
- *Depends on who is on and their experience. No clinical lead.*
- *Not as good as it could be. There are generic and could be more personalised. The care plan could improve to capture changes.*

Care plans can take a lot of time:

- *Time can be a squeeze as it is time consuming – have to make time.*
- *We commission and review, demand is such our service it is not always easy to make time.*
- *The process of reviewing the package of care… If it is a placement – can take a lot of time.*
- *It is a bit haphazard. We plan reviews – they wouldn't necessarily happen at the time and difficult to co-ordinate.*

A number of people considered that there was duplication across the system, sometimes where different teams did not trust the work of another:

- *Not only health but adult social care is paperwork heavy very bureaucratic.*
- *We are doing assessments which seems a duplication of work.*
- *Consultants unpicking other people's work/plans.*
- *If there was ability to have confidence in clinical judgment of others it would save a lot time.*

The needs and technology used by different teams impact on care plans. IG issues are mentioned:

- *When a care plan is done it is coming with medical and emotional information. It is about consent so we don't share information wider.*
- *Our girls make a care plan. Assessment of everything. They post on SystmOne and they will tell us verbally. We add or subtract as we can.*
- *I think they use different way of doing it so everything can be seen by everyone, but IG s a barrier.*
- *One record, people are worried it can be tracked, good that GPs are all going on SystmOne so information can flow.*
- *Access to computer and time make it difficult. Constant changes on SystemOne and we aren't told about it.*
- *Has changed peoples' life, better way of communicating info, via SystmOne.*

How would you like to feel if it happens again?

Staff comments relate to the IT systems which support care plans, and importance of having confidence in the plan.

- *If there was ability to have confidence in clinical judgment of others it would save a lot time.*
- *I think our care plan would be hard, things change.*
- *Care plans do get reviewed but they keep adding on to system 1 [SystmOne]. Things always changing. When we come back off leave we feel lost. You blink your eyes and something is changing.*
- *Important so that patient receives correct care needed and provides continuity – everyone knows what patient needs.*
- *IT systems that communicates with everyone.*
- *Keep care plan steady for a while helps continuity if stays the same or needs to be re-written all the time*.

10. Employer and team support

There are mixed feelings about the support given by employers or teams. Some teams feel they work well together while for others there is a feeling of "them and us", where staff do not work as a team. Agile working is reported as reducing team contact. The importance of training and learning opportunities is mentioned.

Some respondents describe their positive experience of team work:

- *Quite good team work together.*
- *It is much easier and good for the resident if all of us work as a team inside and outside care home.*
- *Management are very supportive about work and private issues – physical support – don't feel you are on your own when making difficult decisions.*

- *Regular one to ones and catch ups …Supportive environment. Managers will step in and liaise with the hospital teams and agencies if required.*
- *Excellent, great team -we work together as a team should work and have a good manager/ regular meetings and updates.*
- *We work like family really.*
- *Support for upstairs could be better. Definitely the glass ceiling.*
- *Everyone is inputting. Good communication in the team from top to bottom, If I say I am really worried about patient then my manager is worried – everyone is worried about my patient.*
- *As a whole the team and my colleagues we support each other.*
- *Emails with organisational interaction. Feel connected to the organisation.*
- *Some of the team are supportive – equipment is poor.*
- *Really like my manager and she’s really supportive.*
- *Good line management support.*
- *Small team, everyone works well. Good familiarity.*
- *I think we get good support. It is such a big company. We don’t see big bosses. Our operational lead is here…we can always contact, If someone is having a bad day.*
- *Only have to ask if struggling.*

Others feel that teams are not working together or need more support:

- *We still work in social care services and community, acute.*
- *No I don’t feel I work as a wide team. It is just us against the world.*
- *It is very much us and them with social care.*
- *Team support could be better. The team could work better.*
- *Whistle blowing is political and tricky. It is close for comfort. The organisational structure is trickier. Hierarchical structure difficult.*
- *Senior managers don’t appreciate what go through on daily basis.*
- *Different priorities which are a battle, I have health staff told one thing by LPT and I am telling them something else.*
- *“Staff greatest asset” – this is laughable… We are ignored.*

Impact of agile working:

- *Agile working is what we should do…. you are constantly getting messages 8-9pm. It has got to stop. As a team we are good at supporting one another – but need some back up.*
- *Everyone wants to support each other but so stretched just get through the day. Now Agile working don’t get to see each other.*

A number note the importance of training and learning opportunities:

- *Attending a few more courses/refreshers.*
- *Do get given time to attend workshops on supporting staff in workplace lots of training.*
- *Training is more available.*
- *Help with training to keep me up to date of changes.*

How would you like to feel if it happens again?

Staff would like more support from their managers, to feel that their work is valued and greater opportunities for training.

- *Different priorities which are a battle, I have health staff told one thing by LPT and I am telling them something else.*

- *Time and clinical pressures means that can't be freed up [for learning reflection].*
- *Would like enough time to spend with service user and enough time to write up a thorough assessment.*
- *Emphasis on getting to know staff and development opportunities.*
- *Senior management need to be more hands on.*
- *Attending a few more courses/ refreshers.*
- *Manager needs to change and be more appreciative of staff.*
- *Can't get more staff, then shouldn't take on the work.*
- *[Managers] are in the background but they should be here.*
- *People feeling they have been listened to and concerns taken where need to go and responded to.*
- *Had chance to see each other, proper handover.*
- *No-one says thank you, everyone stressed.*
- *What can you do as there is pressure from above.*

11. My own health, wellbeing and personal resilience

Staff report that their job has an impact on their wellbeing - they feel tired and stressed in particular where there is a heavy caseload. Different staff groups respond differently to the pressure some reporting their individual coping mechanism. The actions, put in place to support staff when they are ill, vary.

Staff note the impact on their own health and wellbeing:

- *I feel stressed and tired sometimes. Not physical but mental.*
- *I live for what I am doing.*
- *Sometimes I forget to eat… I am a smoker when I am here. It is stressful.*
- *Emotionally resilient at the moment. Supported to a degree with my own health issues – under pressure not to be ill…Not taken into account that we are on the front line and are exposed to illnesses.*
- *Sometimes we give too much and we can be unwell ourselves.*
- *I was struggling.*
- *I feel fine – no concerns.*
- *Exhausted because beginning to accept can't offer care we want to give. Find hard as don't come to work to do a bad job.*
- *I think we are all knackered.*
- *Resilience not good at moment due to personal circumstances… Sometimes I feel all of these - (exhausted, proud, stressed, fulfilled, anxious, happy).*
- *It is exhausting. Home life is brilliant – wouldn't be easy if had problems at home.*
- *Can be a physical and mental challenge due to poor staffing levels.*
- *Just returning from stress related sickness. Don't feel stressed now.*
- *Strained but not too stressed.*

The varying levels of pressure have different impact on different people:

- *Up and down – pressured team. At the moment - things are okay but depends on the complexities of cases.*
- *Volatile job.*
- *It can be really stressful – the amount of cases you have.*

- *Generally okay. Can have really stressful times depending on the cases that you have. Can be frustrating. Rewarding job.*
- *Up and down – pressured team.*
- *It is very stressful. You get up to come to work – smile.*
- *I feel happy. Satisfaction in job and proud.*
- *We do feel exhausted sometimes.*
- *Days I think why the hell am I doing this.*
- *It's not an easy job. It's challenging and getting more difficult. I do enjoy it.*
- *Work related stress has been worked through have come back stronger.*

Staff coping mechanisms include:

- *It is ok when you leave. I manage to switch off - here I have one to one with team leader every 6 weeks- can discuss challenges. When I worked in Macmillan I had resilience training.*
- *Need to switch off when go home to keep my own sanity.*
- *Health ok, running making time for myself physical health helps mental health.*

How staff health is managed at work varies:

- *If poorly they support you.*
- *We pay lip service with staff health on the face of it… It makes me cross when we are caring for everyone else and then can't care for own when it's our family, our policy prevents this which makes a mockery of it. We have mindfulness policy and we haven't time to do it.*
- *My health issues have been supported in fairness the team have been good with me after taking maternity leave, I was referred to physio when I needed treatment. In fairness I feel I can go to someone and talk.*
- *There is mental health support if you get stressed.*
- *My work-life balance is tight but they were good with me. Team members have gone for negative reasons.*
- *Things have been put in place.*
- *The person (member of staff) needs to be proactive in getting support.*
- *Mindfulness training helps. Regular meetings.*
- *Have been ill the team have given me support.*
- *Been to occupational health as I have a back injury – but I don't feel they have helped. I referred myself to physiotherapy. Not very supported with my health issues.*

How would you like to feel if it happens again?

Staff want to know that they have done a good job, but without stress, be able to switch off when they go home but know that concerns will be addressed if they arise.

- *Downtime reflective time without being badgered.*
- *Need to switch off when go home to keep my own sanity.*
- *Feel I go home and give myself a pat on the back if it went well.*
- *Bosses that listen and open their eyes.*
- *People feeling listened to and concerns dealt with.*
- *Love to feel stress free.*
- *Nice to feel come in to work done a good job in the time paid for and had a break in the middle of the day. All patients well looked after and had all they need that day.*

1. What would give you/is giving you confidence to provide care for people as part of a multidisciplinary team

Factors affecting staff confidence include good communication and confidence in other members of their own team, good working relationship with other teams, confidence in their own work and abilities, and positive relationships with carers and patients. They would like better shared systems to support their work and more training opportunities.

Communication and confidence in other people in the team:

- Good working relationships where knowledge is exchanged.
- *Not just saying good morning.*
- *Communication – you need to be kept in the loop.*
- *I work with a team with the same level of experience and feel a part of the team.*
- *Competent workforce who know what their remit is.*
- *Support from wider MDT. Training supervision. …. Somebody to listen to you when you have a moment – part of a team – 'not on your own'.*
- *Having them on site.*
- *Sometimes it is variable… social care it is always tit for tat. …we have a lengthy form to complete to refer. It takes a long time, there are hostilities, it is us and them… Other departments don't know who the ICS services are.*
- *The hospitals and GPs do not know what ICS is, It is getting better. Appropriate discharges, inappropriate referrals.*
- *Having a dedicated contact name – e-referrals works well.*
- *It stops working when we don't have the correct staff.*
- *I can contact my colleagues and get advice if needed.*
- *If one service lets you down then it is difficult.*
- *As ICS we are first point of contact – shouldn't we have first priority for physiotherapy?*
- *Individual members at present still have drive and pride in their roles.*
- *Trusting assessors' judgement.*
- *Knowing who the manager is on the day if I need to speak to them.*
- *Robust clinical pathways.*
- *Know what each other's roles are.*
- *Greater strong capable local team leadership.*
- *A culture of trust and openness rather than blame.*
- *More staff with right skill mix and tighter supervision of new starters.*
- *Communicate an holistic approach rather than everyone having a little part in it with little communication.*
- *Working as part of a team.*

Relationships with other teams:

- *Better communication between teams.*
- *Not met the discharge sisters, I don't have regular contact with them. Be good to have a weekly catch up meeting.*
- *When you liaise with social services, care providers, etc.*
- *Attending MDT managements at GP practices.*
- *The only way you'll get an idea is meeting teams and the opportunity just isn't there.*

- *Services working better together across health, social care and the voluntary sector.*
- *Building effective relationships with the MDT.*
- *More understanding of other services and joint working relationships.*
- *Direct communication with a district nurse not just via paper referrals.*
- *Joined up resources and triage.*

Confidence in your own work/ abilities:

- *I am fully up to speed – everything in place tough as a brush, agile working. Happy that is me.*
- *Ward manager saying I have got your back when I make decisions.*
- *My confidence comes from being with LPT since 1990… Because we don't have many incidents that gives you confidence.*
- *Feeling ownership of what can provide.*
- *I'm confident in my work because of my experience.*
- *Good system, don't send out unless you have been trained and confidence is ok to do tasks.*
- *Knowing done a good job.*
- *I am familiar with this setting and this gives me confidence.*
- *I'm confident in my work because of my experience.*

Working with carers at home, and patients themselves:

- *Feedback from who supports them at home.*
- *Having a family member's telephone number for problems would be useful.*
- *Patient outcomes/rapport/feedback. Trust and understanding build with patients.*
- *Working with specialists to assist with managing patients ie self-care.*
- *Knowing done a good job.*
- *Getting them up and going again, it's nice to see.*
- *Time to interact with patients and carers.*

Shared systems:

- *Better contact with community, share systems would give me confidence.*
- *Need knowledge on thresholds for Services, Complaints, Safeguarding etc.*
- *Keeping up to date with what is out there – what we can and can't support with - knowing what other agencies can put in – voluntary sector …. Would be brilliant to have access for SystmOne.*
- *In terms of GPs it is about getting hold of them If they are on SystmOne that is great. If not, it is a nightmare.*
- *Ease of communications with other team members within the community works well as on SystmOne.*
- *Share systems would give me confidence.*

Training:

- *Opportunity to train, training portal, mandatory training that must be completed.*
- *Knowledge skills.*
- *Training supervision.*

2. What makes your job easier?

Staff report that their job is made easier by supportive colleagues and leaders who work well together, and good relationships with other teams. Knowing that they have done a good job is important, as are training opportunities. Staff want enough staff, more time and the appropriate technology to do their job.

Having supportive colleagues and leaders in the team who work together and support each other:

- *Support from colleagues and managers - being listened to, not just lip service - taking positive action.*
- *Working together.*
- *Knowing I have support to make appropriate decisions.*
- *Working within a team who have the same aim to improve patient care and strive to utilise resources effectively to enable this to happen.*
- *Most of all it is staff who you are working with.*
- *Good communications with MDT and understand expectations of everyone.*
- *Working together.*
- *Access to quality management decisions.*
- *Receptive senior management – open to suggestions.*
- *Having a good team and Management ...team away days to get people together.*
- *When everyone does their job.*
- *The team, very good team – if you have a good team behind you.*
- *Work together as a team… and everything works.*
- *Everybody knowing their own role, everyone is important.*
- *When we have the support from staff – the more support the admin have the easier it is for you.*
- *Supportive colleagues couldn't do without them.*
- *Some suggestions taken on board some not but I feel listened too.*
- *Support from the secretaries (have to ask).*
- *When I know that I've sent a message and it's dealt with.*
- *Delegate and know job will be done properly.*
- *Less of a blame culture would make work easier.*

Appropriate staff levels:

- *To have all staff on shift.*
- *Having correct number of staff.*
- *Enough staff, wards have defined staffing levels.*

Relationships with other teams:

- *Staff in community not aware.*
- *Communications with agencies.*
- *If I ring someone – I need a doctor to come out.*
- *If it is not a case of tit for tat with social services – it makes it worse.*
- *We have trouble getting things at weekends; your assessment should be verification for why you need it. But you have to justify again.*
- *Community teams willing to problem solve to get patients home and not pass the responsibility from team to team.*

Knowing that they have done a good job and patients are safe, with positive feedback:

- *No one falls, nobody is sick and everyone is happy.*
- *As long as patient is safe and family is happy.*
- *I think just seeing someone who is content with what we are offering.*
- *Treat people how you want to be treated.*
- *It is going into patient in crisis and sorting everything out.*
- *Robust clinical pathways.*
- *Clinically confident.*
- *Patient/problem lead pathway to get best result.*
- *Someone telling you had done good.*
- *I think just seeing someone who is content with what we are offering.*
- *Positive morale, feeling valued.*

Time to do the job:

- *More time please!*
- *Time with patients.*
- *Time to do it properly.*
- *Having time to make decisions.*

Technology support:

- *IT equipment/ mobile phones when working across different sites.*
- *Agile working – log on anywhere.*
- *Technology- up to date.*
- *Having all equipment to do job.*
- *Whatsapp.*
- *GPs on SystmOne.*
- *NHS and ordering equipment for people is not good, It is just time wasting.*
- *Everything on SystmOne…you go in and don't know what is set up.*

Training / CPD:

- *First of all to do a job properly you need training.*
- *Having staff that are trained to right level.*
- *Normally training is available…Some training...not yet available.*
- *Having protected times for personal development.*
- *More wellbeing services for staff.*
- *Setting right training.*

3. What makes your job harder?

System issues which make the job harder include lack of time and staff which increases the workload on staff, poor working relations within teams and with other teams (in particular social care), lack of access to IT or cumbersome systems and processes, and lack of training and resources. Relationships with patients and families are difficult where expectations are not met or there is a lack of communication.

Workload - Lack of time:

- *Don't want more hours, just more time with patients.*
- *Not enough time – want clock to stop.*
- *Coming to base to pick up supplies when not factored into time and away from geographical area.*
- *24/7 culture.*
- *Not enough time or resources to do an excellent job.*
- *Constant pressure of time, interruptions.*
- *Caseloads that are too big.*

Workload - Lack of staff:

- *When you don't have enough staff.*
- *Staffing is massive problem and demand on staff.*
- *The workload can be challenging.*
- *Staff sickness/ leaving staff.*
- *Time is the biggest thing – short staffed.*
- *Stress in the office with not enough members of staff.*
- *Staff sickness/ leaving staff.*
- *Not having the staff to cover the beds.*
- *Sometimes we don't have any support at the weekend.*
- *Obviously not having enough people in team.*
- *Travelling too far – get tired/ exhausted.*
- *Poor staffing and long waiting lists.*
- *Lack of staff in the team.*
- *Lack of staff, unrealistic expectations and undefined objectives.*
- *Ever increasing extra duties and tasks to complete.*
- *Covering for sickness and annual leave.*

Relationships within team:

- *The staff you are working with and who is in charge.*
- *Trying to work together is a big challenge to overcome.*
- *Someone making reactive, ill informed, unprincipled hasty decisions doesn't help.*
- *Over justifying everything – disconnect waiting for services to deliver equipment… Keeps staff away from patient taking time.*
- *Not being kept up to date. Communication from both sides.*
- *Lazy colleagues.*
- *Band 6/ 7 – tend to be on early shifts not later or weekends. Why not share the workload?*
- *Clinical decision taken from us.*
- *Running out of ability to put up with being used and abused.*
- *Human Resources do not follow procedures for change.*
- *Direct boss no handle on team and how to manage people.*
- *I keep hearing about new things coming in. You hear about it – Chinese whispers. We need to hear things formally.*
- *When senior leaders are risk averse.*
- *Hierarchy can sometimes be an issue within an MDT.*
- *Feeling powerless to influence change.*
- *Not understanding what responsibilities lie with whom.*

- *Unsupportive management or management who do not understand the work the individual is being asked to do.*
- *Politics and the divide and conflicting priorities between operational and clinical leadership.*

Interaction with other services:

- *Services that are not available. Long waiting lists as they won't be discharged safely.*
- *Access to services not possible…not timely.*
- *Lack of knowledge. What is out there?…Sharing information between services is important.*
- *Bureaucracy and IT are a nightmare.*
- *Assumptions without checking capacity.*
- *Long waiting lists. Demand/capacity.*
- *Obstruction from outside. Outside factors. Not being able to refer on particularly to NHS agencies.*
- *It is the ongoing hassle it is the GP service.*
- *Resistance from other services/questioning.*
- *Services don't tell us when things change.*
- *Not being fair and equitable across LLR.*
- *No face-to-face contact with other ICS teams.*
- *East Midlands Ambulance Services (EMAS) – response times terrible.*
- *Boundaries and silos relating to how services are commissioned.*
- *Organisational boundaries.*
- *Poor / misleading information at discharge from Acute Hospitals.*
- *Lack of knowledge on what and whom to refer people.*

Relationship with social services:

- *Accessing social care.*
- *Juggling the dichotomy between health and social care.*
- *Social services – waiting and waiting for something to happen. They need GP, ICS, DN and social care all sitting together.*
- *Delays in availability of social care packages and awaiting other NHS and other agencies assessments.*

Systems and processes / IT:

- *Bureaucracy and IT are a nightmare.*
- *Not having access to systems.*
- *Re-doing paperwork.*
- *The amount of paperwork we are supposed to have a paperless system, it is endless.*
- *A lot of paperwork sending faxes… Filling out forms.*
- *Equipment and IT – phones are rubbish. …. Computers don't work patients notice it, poor wifi connections… More than 50% of my day is paperwork rather than seeing patients.*
- *Poor equipment.*
- *IT systems not talking to each other.*
- *Surgeries not on SystmOne.*
- *Technology in general - when it doesn't work.*
- *Duplication – asked to do the same thing – ie: electronic but still have to complete forms*
- *Emails – don't hit 'reply all'.*
- *Autoplanner.*
- *Paperwork better with SystmOne – task orientated.*

- *No direct timely access to investigations at Acute hospitals other than via A&E.*

Lack of resources:

- *Not having the correct tools for the job.*
- *Lack of resources e.g. equipment funding.*
- *Access to resources.*
- *When patients haven't got supplies – dressing and things.*

Lack of training:

- *Lack of training.*
- *Being asked to do something you are not trained or experienced enough to do.*

Relationship with patients/ families:

- *Patient's expectations. Long waiting lists. Demand/capacity.*
- *Not being able to offer services patients' needs.*
- *Prevention is the key thing, a lot of things they have taken off us.*
- *Difficult relatives.*
- *If family keep things to themselves and don't share it makes is difficult.*
- *Demanding patients.*
- *Dementia requires 1:1 / Violent patients.*
- *Poor referrals (from hospital) – don't know why visiting patient and sometimes patient doesn't know what I am there for.*
- *Unnecessary referrals.*
- *Hospital could show patient what to do – district nurse not required.*
- *People don't want to look after family members anymore.*
- *Patients' expectation.*

4. **Think about a time when you were able to have a big impact on a patient or family in your current role. What was the difference?**

Staff highlight the feeling of work satisfaction and feeling appreciated when they have made a big difference to a patient of family.

Work satisfaction:

- *Being there for them.*
- *To help them do things that really helps and has impact.*
- *Things were done properly you gave people more time.*
- *I developed a good working relationship with the daughter and wife…Daughter was very grateful… I did the best I could at the time.*
- *Know what the family and patient wants and is all arranged there and then.*
- *Daily and hourly occurrence. Whether small or large.*
- *Brought the family together to find out more about what is going on in the family and then provide appropriate care.*
- *Having time to spend with people makes the difference.*
- *Communications with everyone [involved].*
- *Enabled patient to fulfil their final wishes.*

- *We always make a difference or try to.*
- *They get the best care.*
- *But when you sort it from beginning to end you feel you have done something…just making sure I have done the best for the patient...It is a good feeling.*
- *Collecting evidence to support decision… able to get funding so patient was independent it was so worthwhile.*
- *Involvement in transformation project had work on record keeping and paperwork…. Have access to everything on one system.*
- *That was working outside nursing care, fire service worked as part of integrated team to help provide end of life. It was lovely.*
- *It is rewarding when you hear them say 'couldn't have done it without your support'.*
- *That's total care and is important. Spent time with patient, treated as human being and had a laugh with him and wife feels really supported.*
- *Just going in their face the relief, they are glad to see you.*
- *It's the little things that make a big difference to the patient.*
- *Feel made a difference and makes you feel good as that's what we do.*
- *Good holistic care.*

Feeling appreciated/ thanked:

- *I was happy when family came to say thank you. They come to talk to certain staff and I felt appreciated.*
- *He [relative] thanked me for supporting him.*
- *Enabled patient to fulfil their final wishes… every time visit a patient facilitate some changes/action in their life.*
- *I still see her now and she says I will never forget what you did.*
- *We have loads of thank you from them.*
- *Knowing you have made a difference. The cards and things.*
- *Sent me a card to thank me and told me what an amazing person I was and to keep doing what I do.*
- *I got a thank you from the son of the patient.*
- *Families thanking me 5 years after husband dies.*

Think about the time when you were able to have a big impact on a patient or family in your current role. What made this possible?

Good communication across services and teams as well as time with the patient help staff to make an impact on their care.

Relationship and knowledge of other services:

- *Knowing the services available, being able to communicate the options and then follow through.*
- *Seamless approach from acute to community.*
- *Excellent support from community hospital MDT and consultant.*
- *Knowledge or the services available in the community.*
- *The support of specialist/experienced nurses Dr's.*
- *Knew the district nurses/ health visitors.*

Teamwork:

- *All services pulling together to benefit the patient.*
- *Effective teamwork and utilising members of the MDT to ensure holistic care was delivered.*

Time with the patient:

- *Time to explore all of the issues with the patient and time to complete the necessary paperwork to refer or request actions.*
- *Less rushed and less of a complex caseload.*
- *Years of experience in working with families in their own homes.*

5. What would you change about the way that services are being integrated to improve care for your patients?

Staff recognise that there are areas of good teamwork but that relationships within teams vary. Communication and joint working across all services are important and can be supported by good interpersonal relations. Services would be improved by more time and more staff.

Staff also want closer working relationships and communication with other services, so that they know what is available and can ensure seamless care for patients. One specific area mentioned is access to shared IT systems (in particular SystmOne) and shared records. There are issues around accessing particular services (eg physio, continence, prevention) which would improve the care given.

Staff want to see joined up, timely services which are easily accessible to patients.
On a personal level, staff are calling for more training.

Some areas of good teamwork are recognised:

- *We get amazing support from mental health team.*
- *Massive input area is dietician and nutritional…massive success is working with Speech and Language Therapy Team and dietician. They complement [compliment] us when we get it right but tell us if they don't. Also work closely with diabetes team.*
- *In reach team – they are very supportive.*
- *District nurses generally good. Historically had great relationship… When we have had district nurse we had nurses box with appropriate dressings.*
- *Relationship like with social services they have got to know us through just training and meeting. It is a great relationship.*
- *Fire service is good.*
- *Anything we do with LOROS or Macmillan is amazing, there are no battles with them like everything else.*
- *LPT's pilot scheme to list whereby health care assistant given details of patients… to see if everything was in place at discharge… Patient feedback was that it was nice to have follow up.*
- Relationships with different teams vary:
    - *End of Life team is fantastic team. District Nurses are so pushed and stretched. Bloods nurses are so rude and talk to you like you are a piece of dirt.*
    - *We have had massive success is working with SALT team and dietician…Also work closely with diabetes team.*

  - *HART team come here once a week so improved relationship.*

Issues around communication/understanding across the team/working together:

- *Very basic things – a pack of information on what people do would make a big difference.*
- *They are not embracing a new way of working, people do lose sight of patients when they are having arguments or whose role it is to do something.*
- *We should be involved a lot more.*
- *People working together pulling in the same direction…You need to know what the right and left hands are doing.*
- *Good will has gone.*
- *Single point of access not fit for purpose.*
- *Co-location - Talk to staff more at Loughborough as located here – not as easy with Coalville.*
- *Front line staff being more involved.*
- *Regular reviews from teams eg GPs.*
- *Better communication with all parties involved in patients care.*
- *I would like to think they were all linked.*
- *People not taking well to change and feel threatened by integration not seen as a positive.*

Services would be improved by more time/ staff:

- *Time would make a difference. For example – time between phone calls.*
- *Cover when other people off.*
- *Freeing time e.g. 'time to care'.*
- *In-house nurses rather than nurses coming all the time… having doctors in more than once a week.*
- *ICS – need to employ more staff. Need more managerial support.*
- *Not enough staff at the call centre.*
- *Additional staff/ resources.*
- *More staff.*
- *Have robust HR process to actually employ new staff it takes so long.*
- *There is so much more we can do but there are limitations.*
- *We have lost a lot of nurses – experienced nurses - because of pressures… I don't want to work here in 5 years - I can see what is coming – not nice.*

Interpersonal relations are important:

- *We have one [nurse] that actually lunches with us here. So we have a really good relationship.*
- *Respect for your role – capabilities, boundaries, what you are capable of… communication and working together is key.*
- *More feedback to each other.*
- *Big loss is face-to-face, know some staff, problem is hub where tick box and don't know staff.*
- *With all the area teams, need to integrate more – face-to-face contact and communication. Take the opportunity to meet other teams.*
- *Socialise in group outside work, helps if know people outside work and what makes them tick.*

Organisational relationships need improvement:

- *Couldn't tell you what is happening in Better Care Together. Couldn't tell you goals, impact and what steps are to get there. It would be good to deliver in staff meetings.*
- *Centralised Hub – on rotation/ working together.*
- *The system of contacting the Accident & Emergency primary care co-ordinators worked really well. This is now being scrapped. New system is under trial – don't know what the outcome is going to be.*
- *Voluntary sector not always aware of what's out there. It's underutilised.*
- *Work more closely with mental health, learning disabilities as patients have co-morbidity need to work closer with the other organisations.*
- *We need stronger links with social services to support people.*
- *Let's get rid of unnecessary paperwork and improve communications. Better comms with GPs and social care.*
- *Social care form getting rid of it and goes back to telephone call...Everyone doesn't fit in one tick box form, social care can then ask you questions.*
- *Hospital or assessment didn't tell us.*
- *For phone number don't know where to look.*
- *My experience of social workers around safeguarding is a nightmare.*
- *The help to live at home form is a nightmare.*
- *We are not the best person to deal with this, don't see them anymore.*
- *Drop the organisational boundaries, have a shares budget…Care should be seamless and the patient shouldn't feel the change in organisation.*
- *Joined up working between scheduled & unscheduled care.*
- *More rotation of health care staff across are ie acute/ community vice versa and could make us less risk adverse.*
- *Better integrated discharge planning.*
- *I would integrate them, don't feel they are.*
- *Communication needs to be improved between the acute setting and the community*
- *It doesn't feel like there's any integration.*
- *Improve communication about what is available.*

IT systems (including SystmOne):

- *All have access to the same systems would be beneficial.*
- *All of us use the same system, biggest challenge is acute, social services etc don't have same systems.*
- *Access the electronic database that Health use SystmOne.*
- *Having access to SystmOne.*
- *I spend so much time trying to find out who the care provider is – I don't know why we can't information share… one [IT] system could save time.*
- *Integrated care records.*
- *IT systems setting better to use SystmOne – systems talking to each other.*
- *Direct phone lines between services. Not through call centre, a dedicated line.*
- *Community team have problem accessing records.*
- *Shared IT systems.*
- *Needs to be on a computer system that talks to LPT and vice versa.*
- *All things bought in to make things easier – seem to make it more complicated ie: taking annual leave/ day off.*

Additional services which would enhance care:

- *To be honest I don't even consider physio and other therapists, for community physio it is now over a year to get anyone.*
- *Some families have taken out private physio because of the waiting list [after falls].*
- *I know it will take 10 months to get a physio for people.*
- *You can't get continence staff in.*
- *Issues around supplies for basic care eg incontinence– if you need incontinence packs you might get them in 3-4 month.*
- *Half the time you are chasing them up for physio [for dementia patients]*
- *Biggest thing is there would be more saving of money if more energy was spent on prevention. Dentist is an issue.*
- *Let's get services in to help prevention…Prevention rather than firefighting.*
- *Proactive care should be utilised so more focus and prevention rather than cure ie smoking, diet, alcohol, drugs etc.*

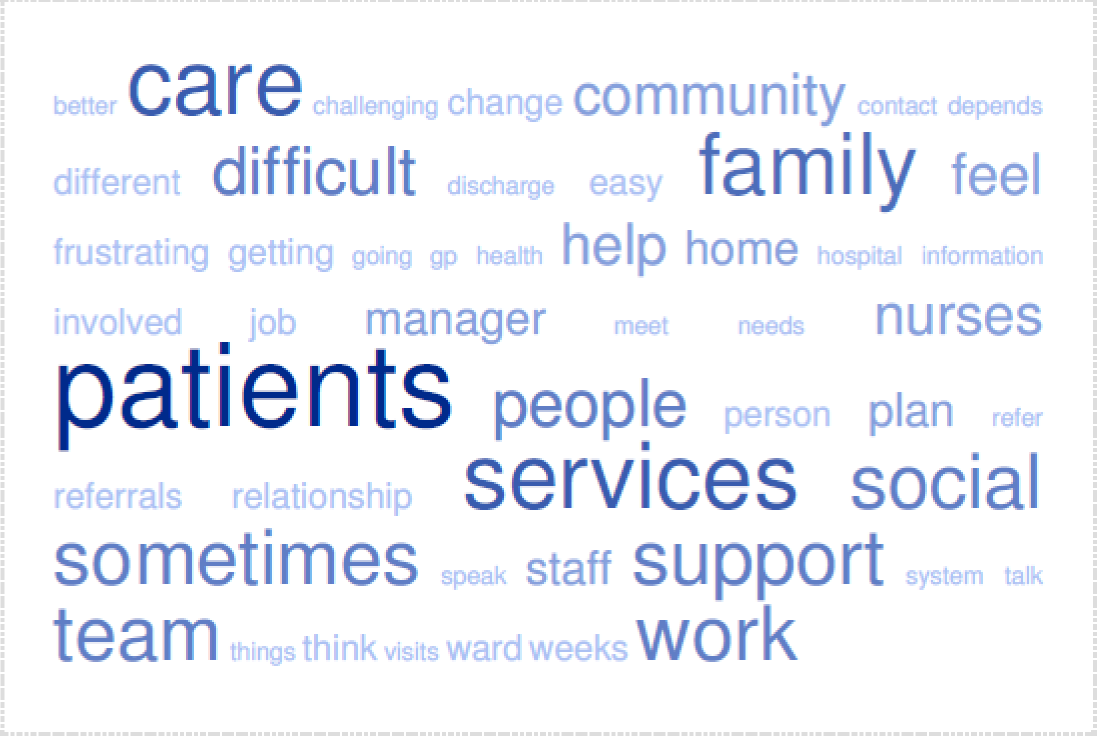
High quality patient care:

- *There isn't the care out there [to support patient preferences].*
- *Working across social care and other teams you…are reassured when people leave hospital that the patient will be ok. When family get involved as well. Have a weekend getting house ready for patient getting home. That is when it works.*
- *Safety of patients is first thing, time should be minimum time to wait for care package. If best care is full, then you have worse service ,and they have to go back into hospital. It is not good for them. CQC should have better strict rules for care companies,*
- *[Care] should happen immediately and not have to wait.*
- *I think more care in house is brilliant, hospitals are full. Best sometimes it is an unrealistic goal.*
- *System confuses patients.*
- *Care plans [not] done.*
- *Initial patient health checks not done when moved service resulting in missing existing conditions.*
- *There must be a better way of dealing with assessment and meeting.*
- *So many mixed messages given to self-funders.*
- *Waiting for secondary care waiting long time.*
- *Patient needs education re sharing records – delays in supporting the patient.*
- *Patients want to stay in own home.*
- *Open wards up again… Is reason [patients] are in hospital due to placement or getting them home.*
- *To ensure that the services provided for our most vulnerable members of society are not depleted as this has a huge knock on effect for individuals and staff.*
- *Services need to be accessible for patients - at present they seem to be closing and patients are having to travel further afield which isn't patient focussed at all.*
- *Care needs to be delivered in a timely way and out-patient appointments need to stop being cancelled and re-arranged.*

Staff training:

- *More training.*
- *Band 3 should have relevant training and at least on NVQ level 3.*

- *Training and on going training for the role of the job is important as lots of tasks cannot be undertaken by generic workers.*



(Key words used across all frontline staff questions)

A summary of themes highlighted:

Building good relations and working together with patients and families are important aspects of the role of frontline staff. They try to involve patients in their care, but this can be challenging where patients and family disagree or do not understand the care available. Staff tell us that time and workload pressures reduce their ability to develop a good relationship with patients and families. Providing emotional support can be a very rewarding aspect of the work but more guidance, training and time is needed.

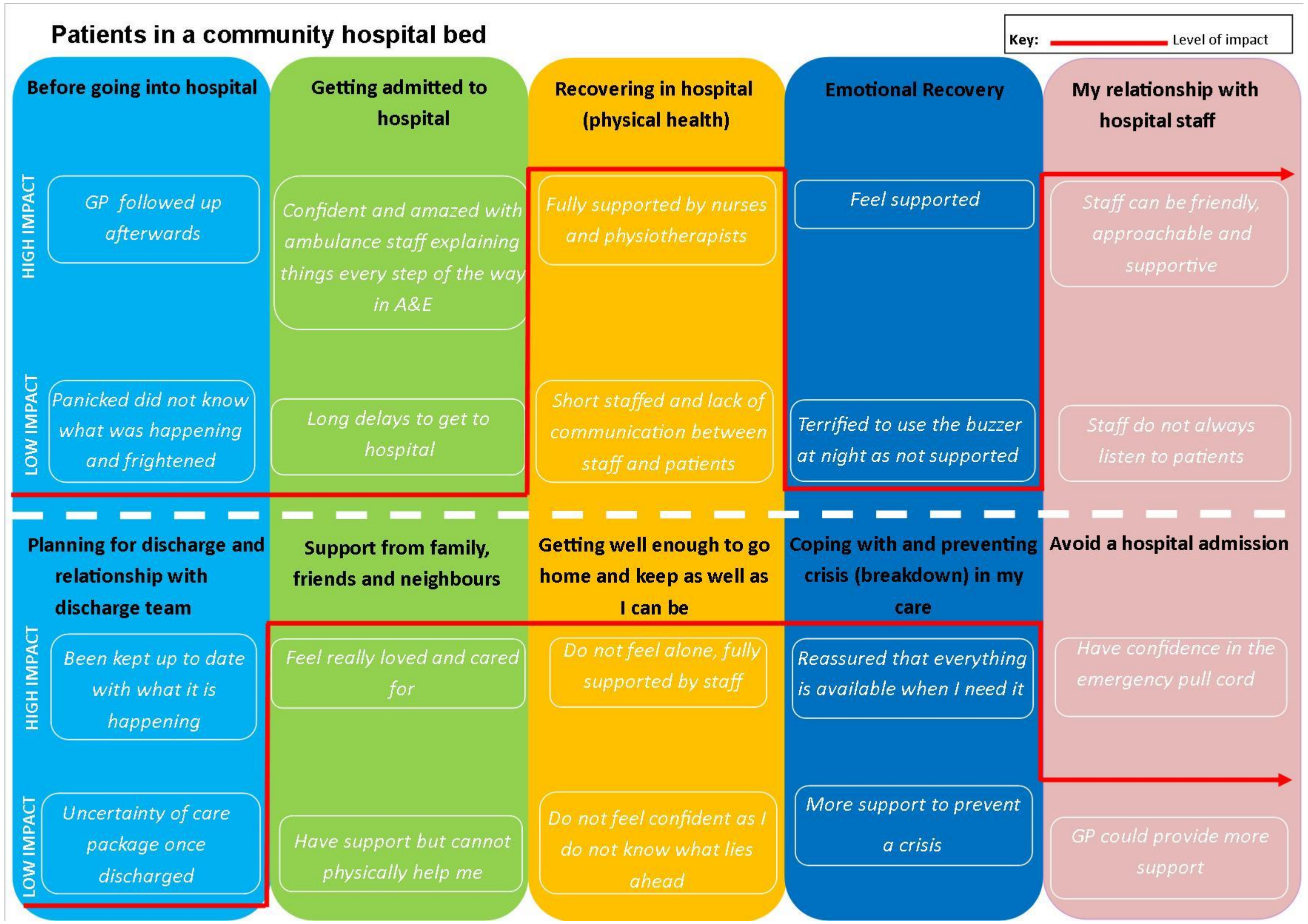
Equally, relationships with other services significantly impact on the care given. Good working relationships with other teams are important - where teams work well together and trust each other to do their job the outcomes for patients are improved. Currently, the quality of these relationships vary but are improved where individuals know each other. There can be issues between services around poor communication, lack of awareness of services or where referral criteria are not clear or understood. Relations with Social Services can be a particular issue.

Staff suggest that IT support, in particular SystmOne, can support closer working between services, eg the referral process. Job satisfaction is important to staff, they want to feel that their work is valued and they have made a difference to patients and their family.

However, they report feeling stressed and tired, in particular where they are short staffed and there is a high caseload. The job is made easier by supportive colleagues and leaders who work well together and good relationships with other teams.

6. Patients in a community hospital bed

Emotional map representing the high impact and low impact points for patients in a community hospital bed.



Patients in a community hospital bed

Key: Level of impact

	Before going into hospital	Getting admitted to hospital	Recovering in hospital (physical health)	Emotional Recovery	My relationship with hospital staff
HIGH IMPACT	*GP followed up afterwards*	*Confident and amazed with ambulance staff explaining things every step of the way in A&E*	*Fully supported by nurses and physiotherapists*	*Feel supported*	*Staff can be friendly, approachable and supportive*
LOW IMPACT	*Panicked did not know what was happening and frightened*	*Long delays to get to hospital*	*Short staffed and lack of communication between staff and patients*	*Terrified to use the buzzer at night as not supported*	*Staff do not always listen to patients*

	Planning for discharge and relationship with discharge team	Support from family, friends and neighbours	Getting well enough to go home and keep as well as I can be	Coping with and preventing crisis (breakdown) in my care	Avoid a hospital admission
HIGH IMPACT	*Been kept up to date with what it is happening*	*Feel really loved and cared for*	*Do not feel alone, fully supported by staff*	*Reassured that everything is available when I need it*	*Have confidence in the emergency pull cord*
LOW IMPACT	*Uncertainty of care package once discharged*	*Have support but cannot physically help me*	*Do not feel confident as I do not know what lies ahead*	*More support to prevent a crisis*	*GP could provide more support*

Patients in a community hospital bed

1. Before going into hospital - How did you feel?

Lonely, scared and frightened:
Before going into hospital some interviewees said they felt lonely, scared and frightened.

- *Alone at home – big house, don't intend to fall again. Taken a while to decide to sell my house – lonely at home now – only see carers my brother said to me what will happen in between – could have a fall again with no one around.*
- *Scared/ awful – last week been so lonely. Had a water infection came here this night [tonight]. GP referral to St Lukes. Patients thought she was going to respite, not hospital.*
- *I was scared as I went to LRI and never been to hospital before.*

Reliance on care in the community:
As interviewees talk about how they felt before going into hospital their reliance on care in the community is relayed:

- *I've got 2 carers who come into my home - now we are looking at having four in place because I can't stand up. This will be with the HART team. I had district nurses coming into dress my legs.*
- *Carer was good and my daughter communicating to me. Doctor was really good following up call.*

The importance of communication:
When hearing how people felt before going into hospital the importance of good communication is apparent as people tell us they felt scared and frightened because they did not know what was going on, confident because those caring for them came over as confident and reassured by staff who communicated they were now in safe hands:

- *Panicking did not know what was happening and frightened.*
- *Feel confident that I would be ok everyone who looked after me was confident.*
- *Frightened – know had a stroke but reassured by ambulance staff that arrived within 10 minutes.*

When asked about the future, interviewees want to feel reassured and informed:

- *What was going to happen and would like to know more.*
- *Want to feel more confident and informed of what to expect.*
- *Want to be feel they were going to get the best health care.*

2. Getting admitted to hospital – how did you feel?

The importance of good communication:
As interviewees remember how they felt when getting admitted to hospital they describe the experience as frightening and stressful. Again the importance of good communication is apparent in order to make the patient experience less stressful and frightening. Many patients describe themselves as acutely ill and unaware of what is happening, however,

even when this is the case, we see from the last comment below, how good communication even during an acute episode allows a more positive patient experience:

- *Don't like hospital; don't know what's going to happen to me.*
- *Coming to hospital is [I am] always scared/ frightened as I last came 11 years ago.*
- *I was confident and amazed on trolley ambulance crew explaining every step of the way in A&E – it was all explained and it was 100% urgency.*

Transport and access:
As people recall their experience of getting admitted to hospital they talk about the time it took to get them to hospital:

- *Necessary - it took 5 hours for ambulance to come was in the same position – fractured my disc at the back. Making it difficult to walk couldn't walk much before.*
- *Called EMAS and I was admitted at UHL then brought to Loughborough hospital. I was in discharge bed overnight as there were no beds I felt stressed and cried tried to get a bed for me.*
- *Waiting a long time from EMAS to get me to hospital.*
- *Come from London hospital by ambulance went well. 3 ½ hour journey. I knew I was being transferred for physio. Just wished it never happened.*

When asked about the future participants want to be treated in a quick and timely manner, to feel reassured and know what to expect.

3. Recovering in hospital (physical health) – how did you feel?

The importance of good communication:

Participants tell of feeling supported during their recovery process. Again the importance of good communication is highlighted in terms of explanation and advice:

- *(Stroke on July 7th in France) with support and activity you have to turn a corner and have confidence to get better. Getting ready to be discharged – have been here about three weeks. Feel supported.*
- *Very supported – given me advice and help explained everything need to know. Will take time to explain everything.*
- *Physical health supported well by staff at Loughborough Hospital.*
- *Get all help from nurses and well supported.*

The importance of physiotherapy:
When participants were asked about their recovery in hospital the importance of physiotherapy is relayed, not only in terms of the therapy itself, but also in relation to the support received from the physiotherapist:

- *The physio in London and Melton have boosted my spirits. You really feel if they have got your interests at heart.*
- *I feel that I have help at hospital. The physiotherapists are very good. They have got me a bed which is compatible to bed I have at home. Communication is not great. No plan for going home.*

- *I feel strong about it, very good physios very good and the care is very good. I feel happy it's nice. They look after you very well and they are pleasant.*

When asked what they would like to see in the future to help with recovery in hospital most participants were happy with their current situation and would like the same in the future. Two participants said:

- *Do not want to wait around to be communicated.*
- *Physio to be able to do their job.*

4. Emotional Recovery – how did you feel?

The importance of physiotherapy in emotional recovery

As people talk about their emotional recovery the link between emotional welfare and physical recovery is evident, particularly in relation to mobility. Participants tell of their feelings of helplessness, hopelessness, along with anxiety about not knowing how or when they can go home. Again the importance of physiotherapy and the support therapists provide resounds.

- *Did feel hopeless and helpless and one time, because not walking and cast.*
- *Sometimes I feel I can't manage sometimes feel I can. At the moment can't feel leg at all, so at the moment not walking.*
- *The family come, I have had three visitors this morning, relatives and friends, I can't see me going home, I have to improve a lot before goes home I can't move my right leg at all. They have measured all my settees and chairs and they are too low. I like my chairs – don't know what they are going to do, I need a commode – my bathroom is quite close but not that good. They have said they could give me a chair commode that sits back into the wall. I carry on hopefully*.
- *Still very up and down emotionally. When things go well with physio I feel confident and ready to go home.*
- *I feel that it is going to be ok. It is not what I thought it would be. It's just not working out as I thought it would – but its early days. I feel better when I have the physios input.*

Participants comments vary when asked how they would feel about their emotional recovery if this happened again, some feel they have been well supported and hope for the same in the future, others say:

- *Wouldn't want to be admitted to community hospital – when you have no family nearby. What do you do? No laundry can be done. It's depressing not building you up.*
- *I would like to feel happy able to walk about.*
- *Having TV and equipment that I can have to help me if I did not have an iPAD it would be difficult.*

5. My relationship with hospital staff – how did you feel

Most of the interviewees felt their relationship with hospital staff was good and valued their friendliness, helpfulness, being listened to and communicated with. Two interviewees did not feel they had a good relationship due to poor communication and lack of compassion:

- *The staff do not listen or consider your position, they expect too much from an older person – they will say I've refused treatment but they don't have a clue. Certainly not happy with the way I am going.*
- *Excellent. I couldn't speak highly enough of the staff. The food here is excellent better than at the other hospital; the physios want to get me home and active.*
- *The staff have been very good. The weekend staff were really good.*

When asked about the future participants said they would like more nursing staff on the ward:

- *There should be more nurse staff as there are not enough!*

6. Planning for discharge and relationship with discharge team – how did you feel

Concerns about being discharged:

Respondents had concerns about being discharged and wanted these concerns to be addressed before they left hospital:

- *I don't want to be rushed and want to be discharged when I feel right.*
- *My brother is helping me with plan for discharge to make sure where I go is safe and I'm not lonely.*

Relationship with the discharge team:

Participants were aware that preparation was being made for their discharge:

- *Been kept up-to-date with what it is happening – going to the care home at 11.30am tomorrow, just got to get through one last night. Social worker came up with the plan – I then organised it all myself.*
- *Having regular conversation with discharge team but not clear when I will be discharged.*
- *Haven't met the discharge team organised hospital bed at home – sorted physios.*
- *Physio went to see the bungalow and moved my rug and settee. They've installed a hoist. Removed all my stuff, they've put a bed in my living room they asked my permission after they've moved my stuff, my legs are worse now than when I came in here. They will then speak to the HART team about getting a care plan and nurses coming in 4 times a day.*

When asked about their desired future experience of discharge patients said they would like:

- *More communication and staff.*
- *Taking advice from discharge team but would like to go home only when I am fit to do so.*
- *Would like to know more about the process of discharge.*

7. Support from family, friends and neighbours

When asked about support from family, friends and neighbours many patients said they felt supported:

- *Feel really loved and cared for. Husband and daughters will be at home support and care for at home. Brilliant! Especially since we've come to St Luke as I live near here. LRI worked really hard to get me back to St Ives – near to home.*
- *Friend and husband support me, they check on me. Family are nearby and they are always in and out.*
- *Son and daughter well supported even when they are very busy.*
- *Excellent support from family and neighbours.*
- *Very good support worker, sister and neighbours support me well.*
- *Well supported from family.*

For some patients the support they receive from family and friends is limited due to where they live, age and other commitments:

- *That is debatable really. They all say they will help if they can, all my friends are 90 – they have lives of their own. My family are very good, I have three sons – one is mentally retarded so he is limited to what he can do, he is a great help, they live close, my eldest son lives close – my son lives at Quorn.*
- *Have support. Can't physically help me – I will need help through the medical services. They have measured the seating in my house already to check the space in my home.*
- *Brother lives in Morecombe – came down at the weekend which has helped. He was able to take me to see the care home.*
- *Feel really loved and cared for. Husband and daughters will be at home support and care for at home. Brilliant! Especially since we've come to St Luke as I live near here. LRI worked really hard to get me back to St Ives – near to home.*

When asked about a desirable experience for the future people wanted to be supported by family and friends

8. Getting well enough to go home and keep as well as I can be

The importance of feeling supported:

- *Don't feel alone. I am supported and confident as like to try and be independent.*
- *Not going back home (Kibworth) too lonely living on my own. Looking forward to going to the care home and being very supported. Got to start putting myself first.*
- *Absolutely supported. Using the frame – had a weakness in turning and going backwards. Team have been working with me to get that right. I feel 100% confident.*
- *Feel confident and supported in getting well.*
- *Well supported and waiting for medicine to recover me.*

When asked about a desirable experience in the future when the time came to go home and keep well people said to feel supported would be important.

9. Coping with and preventing crises (breakdown) in my care

As patients consider how they will cope with preventing crisis (breakdown) in their care the importance of continuing support in the community is apparent:

- *I had carers. I fell off a bus twice, when I come home I have to have carers then, had no NHS staff coming in. NHS staff came and looked at flat and talked to me.*
- *I have a lifeline independence at home and feel confident and used it when I had an accident.*
- *If they were caring for me I probably couldn't do it on my own. I would phone the head office of the carers.*
- *My daughter is a carer and she is with me 24 hours.*
- *Supported by social care/ services.*

When asked about the future the importance of continued support in the community is again stressed. People also require more information on what support is available.

- *Help to stop me going into crisis washing, dressing, making breakfast/ drinks. Taking me to the bathroom when needed.*
- *Not sure what other support or help I can get?*
- *Reassured that everything is available when I need it. Expenses that are occurring that I could get help with.*
- *Advance houses and support workers are always there, not sure what else I need.*

10. Avoid a hospital admission

When thinking about avoiding a hospital admission people talk about how they don't want to come into hospital, some feel they have no control over being admitted to hospital and others consider how they could avoid crisis. Comments do highlight the need to educate people on how to manage long term conditions so that they feel empowered and confident to do all they can to avoid a hospital admission.

- *I know I have to go to hospital. I don't like it and no one wants to go to hospital.*
- *Didn't want to go to LRI, GP agreed so that was a positive experience. But the experience at St Luke's has not been positive.*
- *If it was to save my life then I will go in, I dread night-time coming as I have to wear a breathing mask, I thought I'd be so good and strong, I talked through the options of wearing the 'nippy' mask/machine. I'm not getting on with it very well and I've tried for 18 months. I spoke to one of the nurses and they said my options were to wear it and live, don't wear it and die".*
- *Couldn't avoid admission as had stroke.*
- *Stroke patient – unavoidable.*
- *I had no choice!*
- *Out of my hands as I have complex medical conditions.*
- *Need a smaller place so I don't have another fall – as it makes me worse – physically and emotionally every fall I have had – no more!*

When asked about the future patients said:

- *Attempt to stay healthy; see GP more often; don't leave things before its goes worse.*
- *More information would be good for my complex condition*

1. What give you confidence to receive all your care at home – medical and social

As people tell us how confident they feel to receive all their care at home comments indicate that patients who feel supported at home seem more confident, whereas those who do not feel supported feel less confident:

Feeling supported

- *I feel confident in myself – my GP is ok.*
- *Will have carers set up.*
- *My friends and family will come and see me.*
- *Confidence in GP; support from family.*
- *Staying independent gives me confidence in care home.*
- *Knowing everything is fine in care and being helpful.*
- *Trust in quality medical and social care.*
- *Confidence in GP; support from family.*
- *Knowing that if I call doctor I can get an appointment get prescription when I need it.*

Not feeling supported:

- *It sounds silly – not to go out. But I know I have got to go out, I have a walker and a stick, I don't know what people can provide, it is me to do things really. Having physio when I get home would be useful, my carers will come in and wash me, they used to come at night but I didn't need it at night.*
- *You can ring up a doctor in the morning – can't get through – no confidence. Carers – some you can trust, some you can't, in one week I had 7 different carers. There are about 4 carers that I say are worth having – "I lose all hope to be honest".*
- *Not at all confidence at the moment – carers ok – when the carers are gone – anything can happen in between – lifetime is there but couldn't help immediately if I was dying, I get annoyed as this being old has slowed me down.*
- *Would like a walking frame at home to help me back to independence at home.*

2. What triggers you to seek further help including at evenings and weekends

When considering feedback from the patients to this question it appears that people found it difficult to identify what triggers them to seek further help. A couple of patients mentioned conditions that had led them to seek help but others talked about how they would get help if they needed it:

- *Sore was leaking on bed/clothes so we called GP.*
- *Had a stroke.*
- *Asked my carer if she would come and see me, I've called NHS 111 and I've ended up in hospital.*

- *Would contact NHS 111 if I was desperate and have done in the past take their advice on what to do.*
- *Support worker helps me and she would be my first point of contact if needed further help.*

3. How is receiving care at home different from similar care you have received in hospital

Patients said that the main difference was the constant on hand care in hospital, including access to medical care and equipment:

- *Care at home only comes now and then but in hospital I care 24 hours.*
- *When you're at home its one to one care. That's the difference. I think you get better in your own surroundings.*
- *Care in hospital has all the medical staff and equipment.*
- *Big difference in hospital get dressing done regularly got company. I get food cooked for me don't have to cook It myself it is really good. Cooked meal at lunchtime and evening if it I want.*

4. What is the one thing you would change so you felt more able to manage your condition at home?

The importance of continued support with activities of daily living comes across in the patient interviews as patients consider what would make them feel more able to manage their condition at home:

- *Will need support with washing and helping with meals. Hoping the care home support will help.*
- *Staff, support and friendlessness has helped my recovery. Keep this support going, If they hadn't done what they have for me. I wouldn't be where I am today.*
- *Would like to have more movement (physically) at home and support to do this!*
- *Equipment that can support me at home.*
- *Would like someone to help me get back to independence and stay safe at home.*
- *Carer/ social workers knowing more about my condition. Having the same group of people helping at home from health/ social care.*

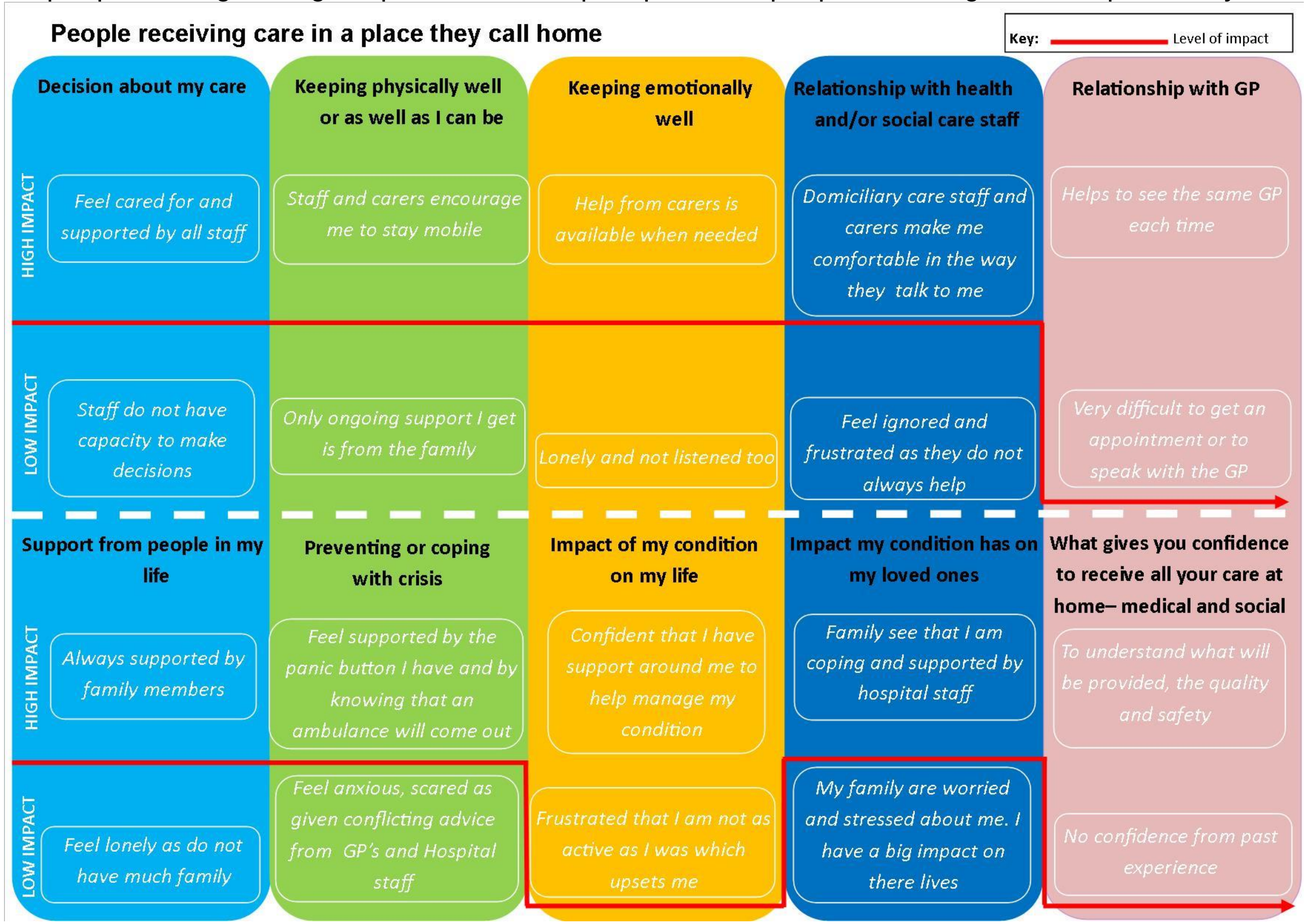
(Key words used from patients in a community bed questions)

A summary of themes highlighted by patients in a community bed:

The importance of good communication throughout all stages of the patient journey resounds throughout and is essential for patients to feel confident, cared for and supported. The need to feel supported is also essential to recovery, wellbeing and confidence and patients demonstrate their reliance on support not only while in hospital to aid successful recovery, particularly from physiotherapists, other hospital staff, friends and relatives but also when they return home.

7. People receiving care in place they call home

Emotional map representing the high impact and low impact points for people receiving care in a place they call home.



People receiving care in a place they call home

Key: Level of impact

	Decision about my care	Keeping physically well or as well as I can be	Keeping emotionally well	Relationship with health and/or social care staff	Relationship with GP
HIGH IMPACT	*Feel cared for and supported by all staff*	*Staff and carers encourage me to stay mobile*	*Help from carers is available when needed*	*Domiciliary care staff and carers make me comfortable in the way they talk to me*	*Helps to see the same GP each time*
LOW IMPACT	*Staff do not have capacity to make decisions*	*Only ongoing support I get is from the family*	*Lonely and not listened too*	*Feel ignored and frustrated as they do not always help*	*Very difficult to get an appointment or to speak with the GP*

	Support from people in my life	Preventing or coping with crisis	Impact of my condition on my life	Impact my condition has on my loved ones	What gives you confidence to receive all your care at home– medical and social
HIGH IMPACT	*Always supported by family members*	*Feel supported by the panic button I have and by knowing that an ambulance will come out*	*Confident that I have support around me to help manage my condition*	*Family see that I am coping and supported by hospital staff*	*To understand what will be provided, the quality and safety*
LOW IMPACT	*Feel lonely as do not have much family*	*Feel anxious, scared as given conflicting advice from GP's and Hospital staff*	*Frustrated that I am not as active as I was which upsets me*	*My family are worried and stressed about me. I have a big impact on there lives*	*No confidence from past experience*

People receiving care in a place they call home

Includes comments taken from both face-to-face interviews and an online survey.

1. Decision about my care

Services users report a mixed picture around service users' involvement in decisions about their care, some felt well supported and listened to while others do not. Family is important. Concerns about care relate to poor timekeeping, lack of communication with GP and DN services, absence of translation services.

Some users report that they are happy with the decisions taken about their care:

- *Needs are taken of, people listening to what I have to say. It makes me feel good.*
- *Well understood and listened to.*
- *Kept informed with what is happening with my care.*
- *Ok, a bit involved. Really looked after at care home.*
- *No problems. I feel involved in decisions about my care.*
- *I need to keep control of things and make decisions.*
- *Brilliant.*
- *Yes I feel involved.*

Some users report frustration and not being listened to:

- *No, I don't decide about my care. I don't understand what it's all about.*
- *No one to listen to me frustrated.*
- *I feel frustrated as can't do things but I manage with my family.*
- *Sidelined/dismissed/ treatment by dogma rather than diagnosis.*
- *Recently marginalised.*
- *ANGRY at how little mainstream psychiatry really cares for us mentally ill… support available is minimal and nigh on impossible to access if you live alone and are unsupported by family/ friends*

Family members:

- *Family are supporting with any decision.*
- *My niece will support me with decision, feel involved and listened to.*
- *No care only my daughter, well understood and listened to.*
- *Discuss care with my husband – husband my carer.*
- *Everything goes to my son, terrible. Son makes decision for me.*
- *After carer goes I rely on my family.*
- *After 8pm and carers have done their day job – you have to depend on your family to help you.*

Timing of care is not predictable:

- *I had a lot of carers…They are always running late. If they don't come I can't go out.*
- *I just have to wait they don't tell me whether they are coming morning or afternoon.*

Lack of communication with GP and DN services:

- *Never see GP and district nurse comes now and then…No one to listen to me frustrated.*

- *District nurses come Tuesday and Thursday. I just have to wait they don't tell me whether they are coming morning or afternoon.*
- *It's a bit of a waiting game, when you get through told someone will ring back.*
- *Getting through to the [GP] receptionist is the biggest barrier.*

Language/translation:

- *If someone is available and translate then we would be fine because I would be able to express myself.*

How would you like to feel if it happens again?

Service users want improved relationship with services:

- *I would like to know that there is someone there to listen to my concerns and to follow up.*
- *I want to decide what I want to do not anyone else deciding for me… don't want to be a "cabbage".*
- *I expect to be treated as a human.*
- *I would feel I was getting some help if they called back.*
- *Involved in all conversations about my care.*
- *If I had some information to help me understand, maybe I can decide what's best for me.*
- *Should be more of a follow up. It was if 'you've had the treatment, rehab, now look after yourself, there was no real follow-up care.*

2. Keeping physically well or as well as I can be

The responses reflect the importance to service users of keeping active and building relationships with others, including family and outside agencies (eg Age UK) to support their mobility, but also feelings of frustration if they are not physically active.

Keeping active is important:

- *I am happy here I have my wheelchair.*
- *Want to keep physically well and able to get around.*
- *Want to feel as physically fit as a I can be.*
- *Mobile with a wheelchair, I am educated and know about my multiple sclerosis.*
- *Not very mobile but make myself as I don't want carers if I can help it. I suppose there will come a day.*
- *Exercise – steps at home – 10 flights a day. 20 metre long garden up and down 20 times a day.*
- *I do a walk everyday weather permitting.*

Building relationships with others, including family, carers and through outside agencies (eg Age UK) is important:

- *I come to Age UK and other groups to keep physically well.*
- *Get picked up to come to Age UK.*
- *Carers help me stay up in bed and chat to me.*
- *Coming to the day centre, helps the person do some physical activities.*
- *Family plays a key role in helping the ladies keep physically well.*
- *If needs help with keeping physically fit – carers help. My daughter helps.*
- *Different nurse each time – difficult to get to know them.*
- *Family plays a key role in helping the ladies keep physically well.*

Inability to keep mobile causes frustration:

- *Feeling low after losing my husband.*
- *Physical health has a knock effect to mental health as not able to do things for myself. I don't feel confident due to physical health.*
- *Frustrated by condition, physically difficult, getting weaker.*
- *Unmotivated due to my actual depression.*

How would you like to feel if it happens again?

Service users experience a range of issues including wanting more help at home, impact on family, their wish to be more active and do the things they used to be able to do.

- *Need physio or help with physical wellness at home from someone.*
- *Would like some help at home no one is listening to me or helping me.*
- *Supported – somebody to talk to able to get appointment with Community Psychiatric Nurse (CPN) can't get one.*
- *I am increasingly becoming more of a burden to her [wife] physically.*
- *Like to feel more mobile, to be able to walk the dog again.*
- *I wish I could go out and do things.*

3. Keeping emotionally well

People report that their condition can make them feel lonely or frustrated, and that those around them do not always understand. In order to keep emotionally well service users keep busy and socialise.

Keeping busy / socialising supports emotional wellbeing:

- *Newspaper.*
- *Garden – walking see birds, cars passing.*
- *Newspaper – reading.*
- *Puzzles to keep the mind active, exercise – keep fit, dancing.*
- *Keeping active – walking around the garden, activities at the day centre. Wordsearch, puzzles to keep the mind active, exercise – keep fit, dancing.*
- *Watching the TV.*
- *Singing/ music.*
- *Knitting, crocheting, singing, sewing – coming here at Age UK I like.*
- *Supported once I am at Age UK.*
- *Loves coming to the day centre.*
- *Listen to religious hymns.*
- *Nice to talk to people in group room but equally happy to be by myself.*
- *Everyone is so helpful if you have a problem you can chat with the carers and get it sorted.*
- *Have other people in church community who have support sessions with.*

Emotional wellbeing can be adversely affected by their condition and when those around do not understand the condition:

- *Depressed when feeling physically unwell with urine infection.*
- *Lonely as I have just lost my husband.*
- *Feel terrible as I can't walk.*
- *The pain is having knock-on effect on mood.*

- *I feel frustrated. Husband doesn't understand condition and will say things that can be hurtful.*
- *Not really listened to as don't think they know how bad I am as I carry on my own.*
- *Angry with my daughter gone to Spain to live. It's as though she has run away.*
- *Depends on if chronic condition is active or not.*
- *Unsupported and neglected.*

How would you like to feel if it happens again?
The responses reflect the importance of social support and family support and that patients wish that they could do what they once could.

- *Maybe need to go out and about more, then I feel better.*
- *I go out and mix with others which is making me feel better.*
- *Need some to listen to me and get support when promised.*
- *Like to feel how I did 10 years ago.*
- *Like to feel 21 again, you can dream.*
- *Condition needs to be explained to husband so that he understands.*
- *I would like to feel on top of things and that people listen to me when I am not.*

4. Relationship with health and/or social care staff

Relations with staff are mixed, while some patients feel supported, others frustrated in particular when they are not able to access services.

Some service users have good relations with staff:

- *They do listen and support me when they can.*
- *Certainly as far as I am concerned relationships are excellent.*
- *Make me feel comfortable the way they talk to me.*
- *I feel supported by social care staff.*
- *I think the Dr's are marvellous.*
- *Good relationship. They are alright.*
- *A few support me, some of them are good.*
- *Very good all have a talk and a chat and laugh. I am included in activities at the home.*
- *Good relationships with carers the GP will come in and see us.*
- *100% - good relationship.*
- *The nurse that I see at the hospital and at the doctors are brilliant.*
- *The care is good but sometimes you need more time.*

Feelings of being ignored and frustration:

- *Frustrated not enough support beyond carer.*
- *Not like family, I don't feel supported.*
- *I feel ignored and frustrated as they do not help when I want it.*
- *Angry.*
- *Ignored, worried and frustrated.*
- *Variable: sometimes just another anonymous patient.*
- *Worried that support will end*
- *Arms length*

Waiting for services affects the relationship:

- *Sometimes have to wait weeks, its help I need now.*
- *Unobtainable.*
- *Not a very good relationship with the GP. Have to wait a long time for appointment.*
- *I just wish when they say they ae coming at a time that they would come.*
- *Come in once a week on Tuesday times to suit DNs rather than us, so have to wait in all morning and sometimes in the afternoon.*

How would you like to feel if it happens again?
Service users' comments relate to continuity of care, timekeeping, and nothing further could be done.

- *Would like a continuity of care and quality of care at home from health and social care staff.*
- *Just keeping up. I have continuity as some carer comes to help me.*
- *Would like to know when coming so don't have to stay in all day.*
- *Nothing.*
- *Don't think anything can be done to improve.*
- *Know me – friendly so they know what I need.*

5. Relationship with GP

Some service users do not know their GP, while others report poor relationships, in particular stemming from the inability to access GP appointments:
While some service users know their GP and get on well, others do not

- *Get on well with local GP.*
- *GP looks after me, it makes me feel alright as he will listen to me.*
- *Don't see a doctor, I keep myself well.*
- *GP is very helpful they got me admitted to hospital without delay.*
- *We see different GP's and they are all very good. Very reassured.*
- *100% - no problems.*
- *Mixed experiences – some positives/some negative.*
- *Disjointed it all depends which GP I see. I feel not listened to, waste of time, worthless.*
- *I don't even know who my GP is...no idea of the name.*
- *Argued with GP as he didn't know as much as me about perfusion anaemia.*
- *Not very helpful. Only go when I need it.*
- *Can't remember when I last saw my GP.*
- *Very good, not really know them, they change.*
- *Don't see GP very often.*
- *It was a locum doctor but he doesn't know much about me.*
- *Supported, always and consistently, objectively too.*
- *Only seen GP once I don't know them.*
- *Feeling a nuisance.*
- *Arms-length*
- *Overlooked in overworked system.*

Inability to access GP services is an issue:

- *Going to doctor is big problem. Don't get an appointment.*
- *Not a very good relationship with the GP. Have to wait a long time for appointment.*
- *No access to appointments.*
- *It is difficult to get a GP or a nurse appointment, and the appointments are rushed when I am given one. I can only attend appointments when I am not working, but am given no choice for appointments outside of working hours*
- *Getting an appointment is a long and arduous task and it's unusual to see the same dr* twice.
- *I don't know my GP. Can't get through to GP because of reception…If I need repeat meds, reception don't help it's frustrating.*
- *Getting in touch with the doctor is my biggest problem…I have told the doctor what the receptionist has been like.*

How would you like to feel if it happens again?
Service users want more timely contact with their GP, and want to see the same doctor to give continuity of care.

- *Would like more contact from GP.*
- *Want GP to come out and see me when I want them to.*
- *I like to know that GP's are there when I need them.*
- *Come when I needed them.*
- *If saw the right doctor I would feel more confident to discuss things.*
- *Should have the name of a GP and be seen regularly.*
- *After named GP retired, we've not received the name of another GP.*
- *Would be nice to have my doctors' care as he knows me.*

6. Support from people in my life

While some service users are well supported by family and friends, others are not.

Some service users are supported by family and friends:

- *Well supported by daughter.*
- *Sometimes it's lonely but friend comes down to help.*
- *From my daughter – phone call and husband.*
- *Fantastic support from family!*
- *Granddaughter and daughter comes every other day.*
- *I am lucky. I have a very supportive family.*
- *My family are very good…I am close to my family and my grandchildren.*
- *Neighbours are very good – ask if I need anything or do shopping etc.*
- *My daughter visits every day.*
- *Feel supported close family, visiting and doing regularly.*
- *I don't have family, friends come to see me.*
- *Sister there if I need to talk to her on the phone.*
- *I am hugely supported by my wife.*
- *My nieces supported me – if I need advice or errands they will happily do it.*
- *Neighbours are very good – ask if I need anything or do shopping etc.*
- *Very good support from my daughters, sons and wife (all of the family).*

- *Son and daughter in law are her carers.*
- *My daughter supports me with my finances.*
- *I have friends.*
- *My son rings me every day. The grandchildren call every so often.*
- *My children help to look after me.*

Some users have poor relations with family:

- *Grandchildren all busy.*
- *Have son who lives near and does my shopping. Daughter doesn't help … My daughter and one of my daughter-in-laws make me feel bad and they don't help.*
- *[Husband] helps as much as he can but sometimes he doesn't understand.*
- *Feel I am a burden to people especially to my daughter-in-law.*
- *They are too busy to see me.*
- *Isolated. Unheard. Misunderstood.*

How would you like to feel if it happens again?
Some service users would like more support from their family but others are resigned to the situation

- *I would like them to ask me if I'm alright.*
- *Like visitors a bit more often.*
- *They do what they can.*
- *They do as much as they can.*
- *Not really it's ok.*
- *Nothing.*
- *Would like to see them more.*

7. Preventing or coping with crisis

Some service users are confident that they will manage in a crisis while others are anxious. Falls are mentioned most frequently as a cause of crisis. Assistive technology can provide reassurance. Service users will call family and use the 999 or NHS 111 services.

While some service users are confident that they can cope in a crisis others are anxious:

- *I am competent and can look after myself to make sure I prevent any crisis.*
- *Yes, I know what to do. The staffs are good.*
- *I've written it all down on what to do if I have a crisis.*
- *I'm a former…'frontline' worker…so I know my stuff where dealing with my possible crises are concerned.*
- *Don't feel safe, don't know what to do in a crisis.*
- *Feel anxious.*
- *Sometimes feel vulnerable on my own.*
- *Very anxious and worried.*

Some users rely on family to support them through a crisis:

- *I will call my friend or family.*
- *I have handed over my affairs to my daughter so she looks after everything. I feel absolutely that I don't have to worry about anything.*
- *Managed to cope with support from family.*
- *I rely on my family.*
- *Ask family members.*

Falls mentioned as a potential crisis:

Falls are mentioned 13 times in the interviews and are clearly a cause for concern.

- *Fall because of low blood pressure.*
- *Fell down – frightened – husband couldn't pick me up.*
- *When I fell rang husband and he came back.*
- *Fell and wife couldn't get me up but neighbour helped.*

Assistive technology/ adaptations (eg Panic buttons/ phones) provide reassurance:

- *I have a panic button which is good.*
- *We have a cordless phone which I keep on me.*
- *Press a button for care assistant.*
- *I have one of those buttons you press.*
- *Have help line.*
- *I have a lifeline for fall etc.*
- *Yes I have my bell.*

Some service users use the GP, NHS111 or 999 services:

- *I've called 999 before… daughter is a carer and has called 111 in the past.*
- *Make an emergency telephone call. Call 999.*
- *Would ring doctors in emergency or NHS 111.*
- *I try to call the GP and make an appointment but it is fully booked.*
- *I know what to do in crisis I would ring the doctor to make suggestions.*
- *I would ring all the 9's if I could.*

How would you like to feel if it happens again?

Again, users will call on family, their assistive technology or health services

- *I'm quite lucky I feel safe as I have my husband. It would be different if I didn't have him.*
- *Real crisis could be with wife and she takes ill.*
- *I would ring all the 9's. I would feel happy.*
- *I press my alarm I do know what to do.*
- *I have a chair lift which helps me.*

8. Impact of my condition on my life

The conditions have an emotional impact, including frustration, but keeping busy and socialising can help.

Emotional impact includes lack of confidence, loneliness, stress, anxiety and frustration at not being able to do what they used to:

- *I would like to have more energy feel less stressed and feel confident.*
- *Sometimes you feel a lot of loneliness.*
- *Exhausted not being able to sleep.*
- *Used to be very active. Grind my teeth. I feel like a burden.*
- *It's frustrating with my arthritis.*
- *Can't get up and do what you want to do.*
- *I can't do what I used to do and I feel frustrated and trapped.*
- *Can't do what I want in case I fall over. At the moment feel frightened.*
- *I feel fulfilled but sometimes I get frustrated as I can't get up and move.*
- *Before I came here I had a good life. It's had a big impact as I am stuck in bed.*
- *Frustrated and angry.*
- *Before I came here I had a good life…I can't do anything I want to do.*
- *Can't do anything. Can't knit now as have Rheumatism in hands. I am angry as it was something to do.*
- *Disappointed – I would like to do my gardening – I miss this. I kept having falls and it was too dangerous to be at home.*
- *I feel that I can cope – my only anxiety is coughing.*
- *It has dramatically changed my life… Can't do a lot of things I used to do.*
- *Sometimes you feel a lot of loneliness.*
- *My condition has cracked me completely… I never expected this.*
- *Shocked me.*
- *ANGRY. My back pain is severe and I feel as if no one can do anything for me*
- *Diminishing quality of life*
- *Suicidal, often, but desperately hanging on regardless, in naive hope*

Keeping busy/ socialising supports management of the condition:

- *If I don't feel good emotionally I like to occupy myself and knit.*
- *I feel great, visits outside care home, go to Age UK Tuesday and Methodist Church Thursday.*
- *Just feel to sit in room and feel relaxed reading paper or watching television.*
- *I live in sheltered accommodation so I have support around me.*

How would you like to feel if it happens again?

Service users are frustrated by the limitations resulting from their condition.

- *I want to do what I want to do – it's freedom I don't have. I want my life back and want my freedom back. How can you do that and give me that back?*
- *I would like to be able to do what I did 10 years ago.*
- *Would like medicine that can help with my condition.*

9. Impact my condition has on my loved ones

The impact on family is mixed, ranging from no impact to service users feeling that they are a burden, and a cause stress/ worry for their families.

Little impact and family provide support and reassurance:

- *No impact – they have their life, I have mine.*

- *I don't make any demands on them and I would hate to think that would change.*
- *My daughter is able to go on holiday. If they aren't able to come in I don't mind we are in touch by phone.*
- *Don't feel a burden – got good community of friends – not lonely.*
- *I'm reliant on my children the local grandson is very good and visits me*
- *Good relationships. Family nearby.*
- *Haven't asked for help but they give me help.*
- *Don't know how wife does it – she is astonishing, very organised, caring, practical, knowledgeable.*
- *My family are very good and care a lot for me.*

The impact on the family can cause the service user stress and worry:

- *They are worried and stressed on my condition.*
- *Worried for them, my husband. Husband has heart condition, takes meds and he is ok.*
- *My youngest son is good to me but gets annoyed sometimes as he has stress problems and gets annoyed when I do silly things.*
- *Worried about son, as he has to do everything. He works full time.*
- *I feel a burden at times and stressed because I can't do what I did 10 years ago.*
- *Difficult when family are busy – they have their own family to look after*
- *I impact a lot on my family and feel a burden.*
- *Had a stroke…The impact is all on my middle son.*

How would you like to feel if it happens again?
Service users would like to feel more capable to cope and have better relations with family.

- *For me not to be so lonely.*
- *I would like to feel fitter.*
- *I would like them to have some sympathy as I think they think I throw myself about.*
- *Like to stay at home.*
- *No impact but wish they were around more.*

1. What gives you confidence to receive all your care at home – medical and social

Service users would prefer to be able to stay in their own home, but realise that this is not always possible. Assistive technologies can help. Family and external agencies are highlighted as important, and where good care is given this gives the users confidence.

Prefer to be at home but that is not always practical:

- *Proud of my own home.*
- *If I could have treatments at home rather than hospital then I would prefer that.*
- *I would love to be at home but if they can do what they can here at home it would be great but…*
- *If I had everything I needed and the hospital staff come to see me.*
- *Some things aren't just practical to provide at home.*
- *There's no place like home – home is priority first place we want to go to.*
- *Not confident. No close family in Leicestershire.*

- *There's no place like home. Having services i.e. pulmonary clinic near to where I live is beneficial.*

Assistive technology/adaptations:

- *If assistive technology is in their home then that gives staff confidence.*
- *Have house adaptations – i.e. pully/ lifeline installed in bathroom.*
- *Suitability of housing environment.*

Support from family and external agencies, both medical and social, is important:

- *Coming to Age UK and my husband.*
- *Your wife.*
- *Need help with housework/ someone to support with clearing the house.*
- *Help with cooking and meals.*
- *Family may not have transport to support loved one.*
- *Would like someone to come in and help me prepare for the next day.*
- *Rely on GP to signpost services.*
- *Sharing of notes across staff and teams.*
- *Sharing concerns – everyone talking. Staff change so often.*
- *I'm happy because I get a lot of support from my family.*
- *Need help with housework/someone to support with cleaning the house.*
- *Help with cooking and meals.*
- *Would like someone to come in and help me prepare for the next day.*
- *Weekly meet up with people.*
- *Consistency of staff. NHS staff not a temporary contract with a regularly changing provider. One point of contact to sort out all issues*
- *No confidence of this in current system. …no continuity = little confidence.*

Good care and support gives confidence:

- *Need good medicine and treatment at home.*
- *I know everyone involved in my care and have built up trust.*
- *The nurse continually keeps an eye on me and asks me what I want.*
- *Could have group consultations. Giving peer support, you learn so much in waiting room.*
- *I feel confident that they are doing everything they can.*
- *Because I know the people.*
- *Knowing that I can make a phone call and someone will be there straightaway*
- *Having carers is very good.*
- *It makes me feel good coming here as it gives me a purpose to come here.*
- *Feel confidence in the nurse changing catheter.*
- *Joined up thinking and effective communications.*
- *But you get everything here. They give you all the details and have more time, it's brilliant.*
- *No confidence at all from experience I have gone through.*
- *Consistency of staff.*
- *A greater sense that they are working together*
- *One point of contact to sort out all issues.*
- *I just feel if I needed someone then they would be there if needed.*
- *Better managed processes and experienced staff.*

- *No confidence of this in current system…no continuity = little confidence.*
- *Better information and communication.*
- *Experience on holiday in Cornwall with cellulitis flare-up. Nurses visited holiday home daily with intravenous antibiotics. Here would have meant hospital stay.*

2. What triggers you to seek further help including at evenings and weekends

Feeling unwell, falls, panic or anxiety attacks can trigger service users to seek help but some users do not expect/ seek help.

Triggers to seek help include feeling unwell, falls, panic or anxiety:

- *If I fall son comes to see I'm ok.*
- *If something happened out of the ordinary and husband was out working.*
- *When I have a panic or anxiety attack.*
- *If I know when I feel unwell and then I let them know felt really tired and down.*
- *When I feel unwell and I can't cope with it I will tell the nurse.*
- *If I felt really tired and down.*
- *Health issues that come on suddenly and can't be managed using existing strategies/drugs and which feel dangerous.*
- *Depression and loneliness panic attacks.*
- *Pain that is so severe I have to do something about it...My surgery doesn't offer weekend appointments, and no nurse appointments after 3pm.*
- *A crisis or something suddenly happening.*
- *Ill health/an emergency*

Some users comment on lack of available support:

- *No GP support.*
- *Unable to speak to anyone during working hours.*

Others do not expect / seek help

- *I no longer ask for help; no-one can help me or there are not the resources to provide the help and support I need.*
- *I simply lock myself in here and cry, desperately and often.*

3. How is receiving care at home different from similar care you have received in hospital

For some service users there is no difference between the care in hospital or at home, while others describe the unfamiliar hospital environment, and lack of individual care given in hospital compared to home.

No difference:

- *No different care from district nurses to hospital care.*
- *No complaints about care in hospital or home.*
- *I don't believe there is a difference.*
- *It's similar.*

Unfamiliar hospital environment and lack of individual care:

- *Better care at home as hospitals are very busy.*
- *Would prefer to have care at home as hospital was too much noise.*
- *Felt lost at hospital. With my husband I'm better at home.*
- *Didn't receive great care in hospital the staff are overworked not enough on and don't get individual care.*
- *At home you get 1-1 care*
- *Feel more supported and not rushed, in a hospital we are rushed to go*
- *I had to go to hospital. I don't want to go back to hospital.*
- *In a hospital we are rushed to go home but we have lots of people around us.*
- *Agoraphobia makes even simple visits to hospital difficult. Local hospital far superior to city alternatives, but home is the least distressing. Travel difficult. Public transport slow, exhausting and too expensive.*

More supported in hospital:

- *In hospital staff are always there to help me but home I feel not supported, other than my family.*
- *They take care of you in hospital.*
- *Hospitals are marvellous but we can't stay there forever.*
- *Can't fault the hospital.*
- *You are not waiting for doctors in hospital, at home you have to wait for some time.*

4. What is the one thing you would change so you felt more able to manage your condition at home?

Issues highlighted which would help service users to manage in their own home include assistive technology/ adaptations, communication from services, relationships with staff and language/ cultural understanding. A range of additional services including out of hours, and rural services are also mentioned.

Assistive technology/adaptations:

- *I would change the bathroom.*
- *Will set up downstairs.*
- *I could get equipment as needed.*
- *I wanted a downstairs toilet…Was told it would be a grant and I would have to repay from the sale of my house, I felt angry about this.*

Communication:

- *Big problem communicating between agencies. Each have own folder nice if had one document. Things get lost, mislaid and people don't talk to each other.*
- *Mostly when you leave hospital – there is no contact it is very impersonal…I felt let down after the fantastic care at the hospital, it's like you 'drop out' of the system.*
- *I would like someone to tell me what's what. The odd time, you need someone to talk to at the end of the phone.*
- *I am well supported when I'm at home or in the hospital. Everything is explained to me and I'm kept informed.*
- *More online health interaction. Skype my GP rather than physically going to surgery*

- *Health Care Practitioners (HCP) having access to Enhanced Summary Care Record (ESCR).*
- *Better information*

Relationship with staff:

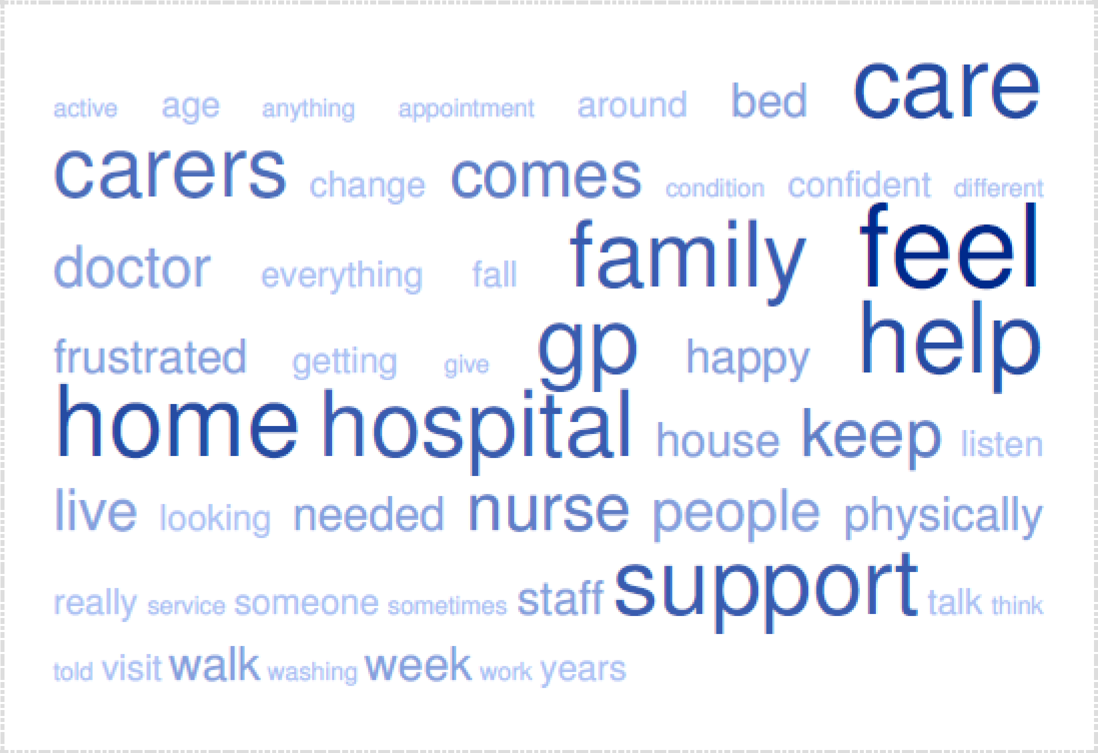
- *Carers – different carers, have to explain the same things to different people.*
- *Get different carers – every time – takes me half an hour to explain to them what I need.*
- *Reliable support from nurses and doctors.*
- *A named professional… to coordinate my care and support*
- *A team that is reliable and that I trust*
- *HCP that have knowledge about my condition without me having to explain, again!*

Cultural/language issues:

- *Understand my culture – eg come into my house with shoes on it is disrespectful.*
- *Language issues having someone who speak the same language and religion.*

Additional staff and services, including out of hours, and rural services:

- *I need, want and cry out for MORE actual, and LOCAL rural care centres…as the nearest ones are city based, miles away so totally inaccessible to us who are trapped living an isolated rural life in the inaccessible countryside, who rely solely on sparse, often non-existent or unreliable, bus services.*
- *Better access to advice and support out of working hours.*
- *Give more appointments outside of working hours for people who work.*
- *More doctors' appointments so u don't [you don't] need to keep ringing 111 or going to A and E.*
- *Appointments at GP surgery – home visits would ease pressure from extended family.*
- *Improve the GP services.*
- *Access to GP or Health professional to commence treatment for chest infections.*
- *Sufficient staff of the right grade and experience to provide continuity of care.*
- *Easy and swift access for specialist support when a chronic illness becomes acute, and better access to quality palliative care.*
- *Not having to wait 3 months for a diagnostic MRI scan.*
- *being able to contact someone quickly and easily*



(Key words used from people receiving care in a place they call home questions)

A summary of themes highlighted by people in a place they call home:

In general the picture relayed by patients in their own home is mixed. Patients would prefer to stay in their own home, but their level of confidence is dependent on support from family and external agencies which can vary.

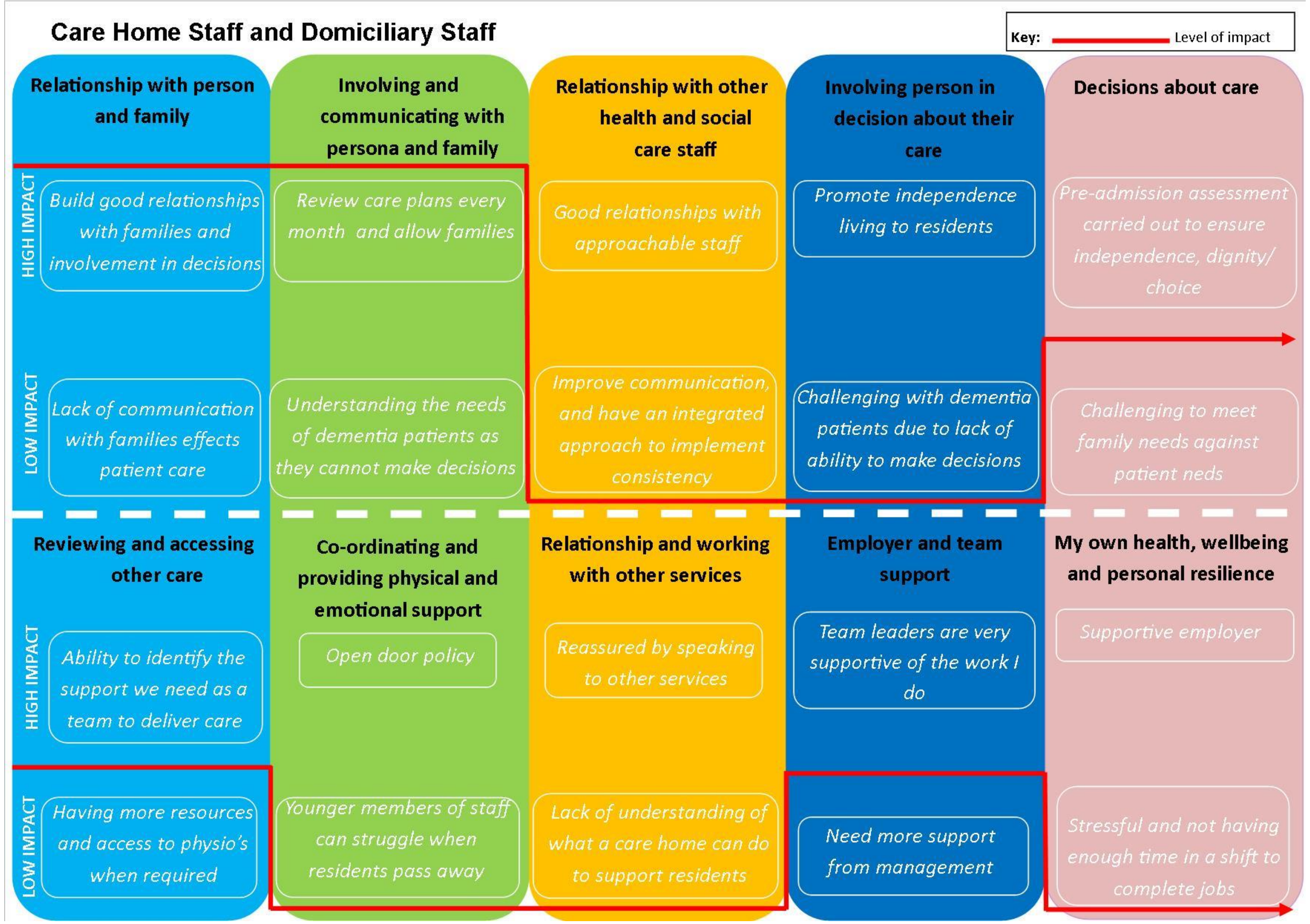
Relations with services, including GP are important. The inability to get timely appointments and to see the same GP, not arriving on time and lack of communication are all mentioned as issues. However, people feel that an improved relationship with health and care services would give them more confidence.

Falls and deteriorating health are frequently mentioned as a cause of crisis. Assistive technology can provide reassurance. Some service users will call family and use the 999 or NHS 111 services while others do not expect or seek help.

Patients can be left feeling stressed and lonely. They would like to do the things they were once able to do. Socialising, involvement in external agencies, keeping busy and physically active are used to reduce the emotional impact of their condition.

8. Care home staff and Domiciliary staff

Emotional map representing the high impact and low impact points for care home staff and domiciliary staff.



Care Home Staff and Domiciliary Staff

Key: Level of impact

	Relationship with person and family	Involving and communicating with persona and family	Relationship with other health and social care staff	Involving person in decision about their care	Decisions about care
HIGH IMPACT	*Build good relationships with families and involvement in decisions*	*Review care plans every month and allow families*	*Good relationships with approachable staff*	*Promote independence living to residents*	*Pre-admission assessment carried out to ensure independence, dignity/ choice*
LOW IMPACT	*Lack of communication with families effects patient care*	*Understanding the needs of dementia patients as they cannot make decisions*	*Improve communication, and have an integrated approach to implement consistency*	*Challenging with dementia patients due to lack of ability to make decisions*	*Challenging to meet family needs against patient neds*

	Reviewing and accessing other care	Co-ordinating and providing physical and emotional support	Relationship and working with other services	Employer and team support	My own health, wellbeing and personal resilience
HIGH IMPACT	*Ability to identify the support we need as a team to deliver care*	*Open door policy*	*Reassured by speaking to other services*	*Team leaders are very supportive of the work I do*	*Supportive employer*
LOW IMPACT	*Having more resources and access to physio's when required*	*Younger members of staff can struggle when residents pass away*	*Lack of understanding of what a care home can do to support residents*	*Need more support from management*	*Stressful and not having enough time in a shift to complete jobs*

Care home staff and domiciliary staff

1. Relationship with person and family

This question highlights the importance of effective communication between a person, family, carers and staff whilst building good relationships that families can trust to support the long-term emotional wellbeing of the resident.

Importance of communication:

- *Very close to resident and families, If don't have any communication. You can't achieve best for residents and look after them. The business is the resident.*

To build good relationships that patients and families can trust:

- *Those with dementia don't fully understand – Important to build trust with patient – Interaction with family can be different, different needs.*
- *Good because we work in our area so get to know them well – regular visitors.*
- *Rely on family for info on Mum or Dad and them to trust you.*
- *Good relationship open and transparent works both ways.*
- *Depends on family, some more reasonable than others and supported them in varying ways. When look round start to develop relationship. Biggest thing is multiple questions from different members of large family. Important to nip things in bud, build trust, be honest, no false hopes.*
- *Important to have good relationship with patient and family. Can be challenging, family think they know better – looking for a second opinion can be obstructive.*

How would you like to feel if it happens again?
It was felt that staff would like to be closer to the residents' families to keep them informed about patient needs and wellbeing and to be trusted in the work they do.

- *Want to be close to resident families.*
- *Understanding of needs – Time varies on different days.*
- *Be open and honest with relatives. Keep them informed of what's going on.*
- *It's better family and services but need to involve care staff, being involved means we can do the best for the patient.*
- *It's open door, make them feel they are the only person we are dealing with as they should be.*

2. Involving and communicating with person and family

This section highlights the various elements that care home staff and domiciliary care staff face in the work they do. Despite that staff feel supported there are concerns around communication, challenges they face and satisfaction in the work they do.

Ongoing communication required:

- *Depends, some families difficult to contact as busy with lives or live far away. We do health review meetings on a date so they can discuss needs and in residents best interest we do. Relations come in office whenever they want. They have my mobile number.*
- *Good communication – Doctors information is explained to the family – We put our points across.*
- *Explaining about dementia and other training. Clinicians come every Tuesday and family can come and speak to team regarding expectations and outcomes.*

Challenging at times:

- *Sometimes frustrating it's our job to let family know – Depends on family, can be frustrating.*
- *Sometime not easy resident say one thing to family which isn't always correct they get confused. Know family relative are frail and don't want to understand it can be awkward. Keep them updated on everything so that they can trust you.*
- *Relative in here not interested. Some asking why doing this/not doing. Last 2 years asked for new skirts, vests. Family only bring in 1 vest 1 knickers, more interested in how many box of tissues in room. If it was my mum I would want to make sure she had enough clothing this makes me frustrated.*

Satisfaction in the work I do:

- *We do alright. Some don't 100% trust us because they are sad and making different decisions. Bad press about care homes puts us on the back foot. Family's guilt. We know we can trust our staff team. Trusted from the beginning.*
- *It's fine – invite to families every month to give them opportunity to ask questions. Review care plans every month. Relatives are regulars. Don't do annual survey.*

How would you like to feel if it happens again?

Staff felt very passionate about the work they do and understand how it can change the lives of patients in their care. At times it is felt that staff would like to do more but are restricted due to the policies and procedures in place. For example; It is felt that families could give staff more permission to buy items for residents as and when required.

- *I am caring person I am hands on. I am a nurse and do shifts on the floor. Feel what's going on. If in the office hear things want to hear better to see for yourself. Get involved in every decision for residents.*
- *Some families I have – Can families give permission to staff to get what they need.*
- *Family door is always open. Family and ourselves work around any issues.*
- *I make time to talk and listen.*
- *Adapt to each individual situation there is no text book to say deal with it this way.*
- *Like to be able to go out and buy the things for residents I wouldn't feel so frustrated.*
- *Feel we make the effort to open dialogue with relatives.*

3. Relationship with other health and social care staff

This question allowed interviewees to express their concerns and suggestions. Although it was felt that some relationships were better than others the key areas of concern are detailed below.

Consistency in services whilst ensuring all teams are proactive and communicate effectively:

- *Communication is frustrating as told different things - no consistency. Lady with pressure sores and dressing need an emergency call out to District Nurses when I know what to do. This is frustrating. If it is soaking wet don't want to call District Nurse when I can do it. They won't let us do it. It is important but not an emergency they are under pressure as it is. Nurses are all over the place i.e. Melton/Loughborough.*
- *Some I know that come into home. Used to have regular nurse now get different nurses for pressure sores.*

Faster response time from nurses:

- *It's ok. Call for nurse, nurse isn't available. Means potential anxiety. Maybe a dedicated Nurse. Nurse will care on their own time. It may not be convenient for patient but also by the time they care the patient has got worse. Sometimes they worry too much and get anxiety.*

Not always being informed about patients conditions/ medicines:

- *It's like chalk and cheese. Doctors are bad at letting us know what they are doing with Meds. Have to ring GP to find out about meds and cream. ICS team are arrogant – remit to get resident up and going.*

Resources within care homes to be addressed according to the number of residents:

- *Good relationship with GP and District nursing team but they have constraints frustrating when talking to SPA need direct number to Deprivation of Liberty Safeguards (DOL's). Issues with ordering equipment for residents. Four doctors in the home at one time is a waste of resource. Then waiting too long when a Dr is called out for a resident. Social care – don't have a lot to do with them. Send reviewing officer who doesn't know what they are doing. CHC assessment passed from one person to another, clearer guidance on how to access this.*

Challenging at times when liaising with other health and social care staff:

- *Not proactive. Overall my relationship with other professionals is good. Social services difficult to get in touch with to speak about the resident. Do reviews yearly. When have reviews social worker saying why have you not done this but didn't meet resident or ring me to see what the need was. It's my job to call social workers, like them to come and meet resident so they know them. They just tick a box regarding level of need they do not know them like I do.*
- *Regular doctors, we don't deal with them seniors do – We deal with district nurses, quite good depends on the staff – Nurses tell us when they come it can be inconvenient. We just*

have to deal with them. Nurses shouldn't come at meal times. Annoying/ frustrating. We have a reasonably good relationship, the same with OT's as well. Consultation with referral to OT can take 6-8 weeks, families get frustrated.

Good relationships:

- *Good team in care home – Good relationship with external staff.*
- *Good relationship. The staff and the approach of staff and district nurses. Doctor's always make time for residents will see another resident.*

How would you like to feel if it happens again?
It was felt that a number of factors need to be considered in order to improve residents wellbeing and care whilst considering the feeling of staff, this includes:

Care home staff would be prepared to increase their responsibilities if permitted by nurses:

- *Be better to have one nurse for an area so get to know them. Few years ago had 2 nurses who we saw regularly. They would allow us to change dressings. Nurses are not consistent with expectations 1 nurse says ok to change their bandage if capable other nurses say shouldn't do it and tell me off. If I know the nurse I can help them out.*

For all health care staff to listen to residents and care home staff:

- *Listen to the residents – Residents ask nurses to come at the time the patient asked – Nurses come when they are eating.*
- *More OT's as frustrating when put in urgent referral and takes 6-8 weeks. Phoned and let you know on a list and approve wait time.*
- *Feel frustrated, lack of respect. Where do you go to make an observation for a better patient experience without going through complaints route? Easy to complain about a care home, speak to us first. Have they got wrong information, rather than escalate.*

Continuity in service:

- *Need continuity in Doctor's services keep changing them lose that personal touch they are becoming colder. I feel frustrated by this.*
- *Put people on the ground to see what it is like in reality the system doesn't work. All want to keep resident out of hospital. Two GP visits a week work quite well.*

4. Involving person in decision about their care

It was felt that staff would like to involve residents more about the care they receive however due to challenges with their ability and family decisions this was not always possible.

To consider how questions are asked to residents and how much information care home staff have:

- *Depends on what it is, sometimes palliative care staff can struggle too, not easy. Spend time with the resident. Wheelchairs can be more difficult ask why need depends on their capacity continence – be careful how to word it so they are not uncomfortable.*

- *Difficult but manage this. When DOL's team come they know more sometimes than we do. I feel incompetent as I feel I am not doing my job, resident doesn't want to talk about if they want to talk about other things.*

Promote independence to residents:

- *Depends on resident. Try and encourage them to take part and make choices.*
- *Like to promote independence, residents can do things themselves but don't as think they are paying for staff to do things for them.*
- *They should be involved but if they don't have the ability to those decisions then you speak to the family or decide what best for the patient.*
- *Absolutely, monthly review, discuss as appropriate. Talk to families.*

How would you like to feel if it happens again?

It was felt that care home staff and domiciliary care staff would like to feel more supported and kept up to date to care for residents to improve patient care whilst increasing the interaction with families.

To have longer time to care for residents:

- *Like to have more time to watch the resident and be there with them. To see what they do and do more for them.*
- *For dementia patients families make decision. Put on 30 min observations for continence condition. Find out more about residents. Continence pads are for reassurance. Can understand families' frustrations, don't raise families' expectations. System change can't get equipment from NHS anymore. Home or families now have to buy chairs etc. Don't know how they will work, as they are expensive families will struggle.*

Ongoing communication with team and families:

- *Home support from care manager on decision; don't get much support from her if resident is refusing to have a bath. Manager needs to interact with relatives to help support our decision.*
- *When families gone to GPs and not talked to us. GPs expect us to be gatekeepers. GPs don't inform us when they have talked to the family.*
- *It's about families' time. They don't communicate with me, amazing to read something about residents that I didn't know. I feel frustrated by this.*

5. Decisions about care

Although some interviewees felt supported in the teams they work in, the key factor highlighted how the communication between families and staff can become a challenge when delivering care. By families interacting more and trusting staff would improve relationships and overcome any concerns they may have.

- *Don't find it easy but I can manage. When don't know the resident get as much info from family, friends who know more about the resident and can make right decision. Family not easy wanting things done in a certain way, but know from professional points of view not in the best interests. Complete DOLs and best interest assessment is involved sometimes* *communication is not here – don't give feedback but paperwork sent with lots conditions that don't always make sense.*

- *Yes we can say what we think but they may not listen.*
- *It's a mixture of both if families don't want it. Some families open minded keep them informed. Don't think we struggle need to be honest with families from day one I keep them informed on resident care.*
- *Don't have a direct input, goes through hierarchy.*
- *It's manageable and frustrating as residents have capacity to do things themselves.*
- *Easy to do right thing. Frustrated if families don't understand. Asking Doctors to do continence reviews, won't give temporary bit before, families have to buy. Doctors don't come in a timely manner.*
- *I do pre-admission assessment to ensure independence, dignity/ choice. Resident and family involved to ensure patient centered care and we can meet their needs.*

How would you like to feel if it happens again?

It is felt that systems need to be in place to help support residents and staff to deliver effective care in a timely manner. The input and trust from families is vital whilst listening to care staff to ensure the highest quality of care is delivered. Further details regarding a residents' medical history should also be provided by GP's and hospitals to ensure all teams can work together.

- *Ideal is to have meetings but they don't happen. Need to listen to each other and decisions of the residents outpatient appointments receive info 2 weeks later phone call would be better if we need to do things immediately rather than waiting for the letter. This is a delay in the residents care.*
- *Need info from family to do the job we do. Families don't always know what to do chat with other staff for ideas and go back to family with solutions.*
- *Would like to have a direct input as we know them and want the best for them.*
- *Like more information on medical history/ allergies we have to trust people. GPs/ hospital have different records seen by Drs in community we need info from them on what is under the dressing. Communication needs to improve need to share info this is now safe guarding.*
- *Nice to get extra support if needed from the in reach team. When needed rather than having to wait a week. Service should be available 24/ 7.*
- *To be taken seriously. They had an experienced nurse with me who undermined me all shift. Always ask if I need help because shes an experienced nurse she can do things better than me. I feel frustrated at her as been senior 10 / 11 years. I know what I am doing and don't like not being taken seriously.*

6. Reviewing and accessing other care

Interviewees expressed their confidence in accessing other care providers when required and appreciated the additional support. It was felt that more information and training could be provided to care staff in order to support residents and avoid hospital admission. The importance of completed care plans was addressed and was felt that this supports staff to understand patient needs.

Working together:

- *Doctors good experience appreciated their support. Nurse on floor resident had catheter that got blocked not easy to put new catheter in didn't feel confident to do this for resident. Rang out of hours (OOH's) and GP said to put new one in. wanted the resident to go to urology. I inserted the catheter, resident still in pain spoke to district nurse told them what I had done and they sent someone out. Had a good chat about resident and went to urology. Would like to do IV fluids as residents come here to die, they are frail and get dehydrated and then have to go into hospital and they are not in their home environment. Would like to be able to give the IV fluids so they don't have to go into hospital.*
- *Its frustrating overall it's all right I'd been away and things change not told until got resident sorted.*
- *Seniors do care plans but we can feed into it.*
- *Physios good. OT good we decide what see on a daily basis given three options and choose the best. Depends how you get on with Drs am comfortable to ask advice and they support even though they are struggling. They can give insulin have been trained how to do this. Something good has come out of it. Help winter pressure care and help with check lists to go from residential to CHC.*
- *Confident in results and assessing.*
- *Capable of accessing care we require don't often come up against a brick wall.*
- *Do as we are told. Helpful if they write in care plans.*

How would you like to feel if it happens again?

It was felt that care staff would like to feel supported and involved to deliver the best possible care whilst being fully informed and confident to speak to families about the right care for patients.

- *When residents are older feel they are not a priority. Resident had private physio as resident goes up and down. Family want a second opinion as can't understand that with each trip won't go back to where they were. GP's don't look at person for behaviours don't focus on this and give tablets and up dosage and it looks negative on the patient.*
- *There is a protocol to follow, so long as it is in the best interest of the patient.*
- *Want to feel supported. If somebody they cared for in community should have a care plan when they arrive at the home. When come out of hospital and had a bleed on brain need to share info with care home team as this may change the resident and we don't know.*
- *Involved a bit more been here 15 years people don't want to tell me anything. I suggest things but they say they aren't doing it. If it is better to do it an easier way but they don't listen. Suggestion re meds I am trying to make it easier.*
- *Mutual respect and communication. We don't need to know – should tell us what has been done so we can write it up. "Can't do holistic care if don't have all the information".*

7. Co-ordinating and providing physical and emotional support

The importance of providing physical and emotional support has been addressed by care staff, this involves knowing that they have a wider team around them and understanding that all feelings are acceptable.

Make time to care for residents, families and staff:

- *Some younger members of staff they can struggle when residents pass away. I make sure they are ok. Explain older people their life expectancy is short. Some staff may not have dealt with death before and are close to the person. Any questions try and answer. I am supported by management they are there. Seek reassurance. Home said it's alright to cry. Bond with certain residents strong. They are poorly given best care you can make sure end of life is pain free and someone there for them.*
- *Most of the time its ok. Nice to know people are there but there is not enough you can trust. It's all about the patient and who they know looks after us.*
- *We always make time. If it's mental health issues proactive in getting Hynca Lodge involved if they know them. We are listened to and our point of view.*

To let residents and families know that they can talk to staff at any time:

- *Sometimes find it difficult. If resident a private person difficult to ask how they feel. i.e. one resident wife died and don't feel can ask him how he feels. If he wants to talk he knows that I am here. I wouldn't approach them I would support them. If ask for a private word will take them aside and help as much as possible. Daughter getting support from us as mum is dying thanks us. That makes me feel my job is worth doing 10 x more.*
- *Open-door policy. Involve families in the journey. Keeping other professionals in the loop.*
- *Handovers between all staff, including all areas of domestics. Somebody is deteriorating we meet relatives when they come in.*

How would you like to feel if it happens again?

Overall most care staff were pleased with the current model and how this supports members of the team, some suggestions were made for more information to be made available and for more privacy in the office to discuss these matters.

- *Death happens. I say to young members of staff they have to be aware this happens in the units. Team feel the same and support each other. No set rule on support. Door open know where I am.*
- *Everything is in place help the patient but what about us as staff.*
- *Nice to know all services are at the end of a phone. Don't have to go through call centre to get to who we need to talk to. Help in areas to call so can speak to them not choose an emergency and build relationship. Put trials in place but it changes often.*
- *Manager doesn't listen find it hard to say and suggest things there is no confidentiality in the office or support from her.*
- *Professionals keep us in the loop. If relative takes residents to GPs, ask them to feedback conversation.*

8. Relationship and working with other services

This question highlighted the concerns and difficulties that care staff face with other services and how this impacts on patients. Although there was some feedback indicating that relationships are good the majority expressed the challenges they face.

Lack of continuity of care across other services:

- *There are good and bad. Some follow up. Some professionals ignore me and I need to go above them to get someone to respond to me and it's frustrating and not right for the resident/ staff and family.*
- *Pharmacies yes, GPs yes, the services are pretty good. Service not good is hospitals. When they have care of our patients and we are not allowed to talk to them. If a patient goes into hospital we can't ring the ward and find out how they are as it's a breach of patient confidentiality as we are not family, we ARE their family they don't have anyone.*

Lack of understanding of the work we do:

- *Lack of understanding on what care home can do. Leave messages with care assistant. Giving notice of when coming, turn up and expect resident to leave their dinner, it's not right. It's the arrogance.*
- *Physio maybe their ideas and ours conflict – talk to them – I feel I can say.*
- *Can be any of those depending on who talking to. Feel let down and not got support to give resident what they need and it's frustrating for us.*

Improve communication between all services:

- *Sometimes poor comms within department. Keep getting phone calls about the same thing. Told to speak to someone and they are on hols or not in monthly meetings with GPs and then put on monthly when don't have enough as they have just been issued and run short, have to keep double checking. Med centre frustrated as well. More problem with GP service as telephone triage and won't come out to see resident with a rash. GPs book calls and don't call back. It can two days which is frustrating.*
- *District Nurses come into the home and they won't come and find us. Surgery don't communicate and this is frustrating.*

More involvement:

- *I don't have a problem. Would like more connection with pharmacy. It's all done at top level not care staff.*
- *Make connection with dietitian/ OT am I happy with measures put in place. It makes feel good and in control.*

How would you like to feel if it happens again?

Interviewees expressed the need for all services to be open and transparent whilst respecting care staff to deliver the highest quality of care. It was felt that current policies and procedures should be reviewed and that the views of care staff are considered and tested where appropriate.

- *Treated as a colleague who is doing everything for their client (resident) I am open and transparent, if something happen I ask for support, this should be reciprocated.*

- *If we suggest something try it and see if it works.*
- *GPs continue with calls from day before and call back rather than us keep chasing or fax through a prescription. Given 30 days of tablets but it is tablet twice a day so only 15 days of tablets. Nurses can certify patient's deaths find frustrating when they pass away at 4:20 am why do GP's wait till lunchtime to certify death and the body has been here for 6 hours and this is distressing for the families. Family's peace of mind want to know loved one is at the funeral parlour. If sudden death is different. If know the person is due to die why can't they go to the funeral parlour and certify the death there. Do EMAS leave older people waiting three hours for an ambulance sitting with resident on the floor.*
- *We are the ones giving the medicine so we should be involved, it's all done at top level.*
- *Nice to have a person to liaise with as build up working relationship if need help we need it not screaming and shouting for the right things.*
- *Ring for GP to come out they are reluctant to come to the home want diagnose over the phone need to come out and see them. ie rash almost blistering see how it goes need to review the residents and see them.*
- *Mutual respect. Other services need to understand can't drop everything we have to support our other residents. Don't want to be told by a physio how to do my job. It's supporting and protecting our residents and staff.*

9. Employer and team support

It was felt that the employer and team support network was positive giving care staff the confidence to speak to employers and express their feelings on a wide range of issues.

- *Employers are good whatever I need to ask and they listen. If can't do a meeting they are there for me. If need equipment they get for me. They check emails for me. Team is like family, look after them my babies, know I have their back and care for them. I will discipline if need to. Help with personal problem if I can.*
- *On the floor feel supported – Employer/ higher management lead not support.*
- *All team leaders are supportive can go and sound off with them. Manager is there for me whether personal, work or staff no problem. Secretaries in the office are brilliant. Nurses I can go to and ask for support and advice. Can go to nurses and ask for advice so doesn't need to always contact GP and look stupid. Build up a bond with them.*
- *Pretty good, manager is approachable.*
- *Investors in People care home. We have good support here. Help support all staff.*
- *We all work well and support each other its almost good communication.*

How would you like to feel if it happens again?

It was felt that improvements in some areas are required which should be addressed once reported. The emphasis of more involvement of care staff in decision making to deliver high quality care was shared across many interviewees.

- *Always something to improve.*
- *Just to be listened to – Explain to them but doesn't go any further.*
- *Need to be more involved.*

- *There is always space for something better working with different cultures important to please everyone.*
- *If don't communicate problem having we can't help you. Need to talk about it don't wait till escalates to crisis point.*
- *Like to feel happier than I do now lots of bickering and back stabbing not pulling together as a team. Feel it's a big witch hunt with certain staff.*

10. My own health, wellbeing and personal resilience

Many interviewees highlight the responsibility involved in their roles and the importance of trusting team members to support them. It was felt that time constraints impacted on staff with a shared view that this should be reviewed further.

Further support required:

- *Just want to run and give up, I need to be everywhere. I don't always delegate when I should do, if I do it I know it is done but need to trust people but tried in the past and didn't happen.*
- *Some days can be exhausting, if resident needs you more – some days can be happy – If physio are in then have to handle that on top of all other workload – work piles up.*
- *It's a demanding job that I can't personally do 9-5. Want to do best for staff and residents. Phone is on 24 hours a day and staff can contact me anytime.*
- *The shift is not enough time in between 3.30pm – 10.45pm on late last night and all back in this morning shifts could be done better.*
- *Do like coming to work some days it goes pear shaped. Do like my residents sometimes have to carry work forward. Do like to pull my own weight.*
- *On a Friday I am dead.*

Understanding of personal and emotional circumstances:

- *Can be stressful but it's not always. When something happens like someone dies. I don't let it show I deal with it at home.*
- *I am fed up with bureaucratic burden dragging me down. I get tired, have a condition that can take charge of me!! I get support. If CQC turned up and I said had busy morning, they wouldn't give a "chuff". Everyone wants a bit of you.*

How would you like to feel if it happens again?

It was felt that more resource is required to manage the current workloads whilst allowing staff to plan effectively and to be recognised for the work they do.

- *Nice to be able to plan day with residents and staff. Staff not to call me on Saturday and have a lie in. Have told staff they can call me anytime.*
- *More staff to help – care coordinator be nice to lighten the load.*
- *I need to sort my head out on days off need to be left alone. Booked holiday and within 2 hours asked to call work and wanted me to come in. they don't leave me alone constantly at me as I won't say no.*
- *To be recognised for the very many good outcomes we have and not to feel just because we are a care home we must have got it wrong. Care home – you should be fit for*

purpose!! Should supply things. People quote document they don't understand. Tell us we should supply equipment when should be NHS/CCG e.g. biometric equipment

1. **What would give you/is giving you confidence to provide care for people as part of a multidisciplinary team?**

Many areas were highlighted, they contribute to providing care as part of a multidisciplinary team including:

Knowledge and training:

- *Confident because of knowledge. Work well with surgery don't need them to come out every day just need their opinion when I need it. Physio work well with them, mention if I have concern call us. Good communication with other services.*
- *More training – pharmacists – more activity coordination.*
- *Training to gain understanding.*

Confidence to ask for help from other teams:

- *Knowing I can do job and go to other team leads.*
- *I feel confident it depends who I am with certain members of staff don't have confidence in as they are more overpowering than I am.*

Feedback on care provided:

- *Feedback from families, visitors, LCC compliance, CQC.*
- *Medication audit from surgery it was all good. That boosts confidence. CQC inspection has good experience.*

Continuity of partnership working:

- *Work as a team supporting each other and learning from mistakes. We are not all perfect. Ask for advice if needed. There are always new ways of doing things.*
- *To be included with MDT.*
- *Surgery doesn't include care home routinely, particularly in EOL care.*
- *GPs decline to come to see patient as not on EOL meds but has repeated TIAs.*

2. **What makes your job easier?**

It was felt that there are a number of factors contributing to this including:

Having a supportive team and line management:

- *Having a good team – Residents in a good mood – Sharing a job load.*
- *Working as a team – good support.*
- *Knowing have support behind me. If struggle with paperwork have support.*
- *Staff and back up – good team.*
- *Structure, team work, access to information, technology.*
- *Having support from management.*

Effective communication:

- *Good communication.*
- *Having opportunity to clarify situations so not escalated.*

Partnership working:

- *Effective discharges from hospital.*
- *If social workers future planned appointments we can then make sure residents are ready and we have information ready, we can accommodate people.*
- *Send discharge summary to GP.*

3. What makes your job harder?

Interviewees expressed the various concerns affecting them and how these factors can impact on their daily work, furthermore the need for these to be considered and embedded were demonstrated by the number of responses.

Levels of administration:

- *Everything. Too much paperwork. Need to be on the safe side prove that you have done everything you have said. Want to spend more time with residents...DOL's is massive amount of paperwork. Getting good staff. Booking and providing training. Getting support from CHC to keep resident safe and ask for mounds of evidence which is right but keeps me very busy. We should listen to residents keeps saying this. Let's see why he keeps saying this to me.*
- *Not being understood by some people. To justify everything. Amount of paperwork if not done then care not happening.*
- *If I didn't have a supportive team. Not enough hours in the day. Senseless reports people want that have no relevance to day to day. Things are changed so often and correct info not sent through. Discharge letters not right. Need to send documentation for medication is important as we can't give to residents if not in writing over the phone is not good enough.*

Staff not working together:

- *People not working together – Information not sufficient about patient – not having a full handover.*

Limited support from team and management:

- *No support. No communication and lack of confidentiality – none in here.*
- *Not being listened to.*
- *Not getting listened to especially if information you passed on and we are not listened to by seniors. We know the patient – Very frustrated, you feel like you're not doing your job – Can't so above and beyond to care for someone, very upsetting. Should only do the standard requested.*

Not having sufficient time:

- *Length of time to send people out to do DOL's assessment. Fax machine doesn't work so DOL's team say not seen review paperwork. So we then have to send by post. Whole process from form to renewal they get paperwork wrong and slows down process. Turn up unannounced to do review so not prepared. DOL's team 3-5 calls about resident from different people, do they not talk to each other. Length of time for DOL's to [be] raised. Don't tell you when they are coming so that you can be prepared for them.*
- *Don't understand can only do one at a time as we need a nurse to be at the assessment.*

4. Think about a time when you were able to have a big impact on a patient or family in your current role. What was the difference?

A number of impacts on patients and families have been established ranging from listening and meeting family needs, getting answers for families and discussing the best possible care for residents as this may be different to what families originally expected:

- *Not best place for residents - grade 2 listed building so can't make big alterations. Resident went into hospital and wife to Market Harborough. Went to assess him in hospital, daughter talked about Father and liked how she talked about her Mum and Dad went back to assess Father and Mother, if you can take both of them before Christmas would be good. They are now both at the home and are really happy together. Have separate room at night but they go out to like the pub and sit in the garden. Family happy that they are both together. I fulfilled my promise to the family.*
- *Taking on what family wants/ patient wants and finding a medium.*
- *I've got residents walking again, we get thanked for that. Depends on the patient and what they want to do. If they feel isolated we encourage them to walk.*
- *EOL care there for resident and family. Family aware of what happening if I can't answer a question I spoke to a nurse. It's about the family.*
- *I can't think of one. Access to health care staff.*
- *The resident wanted to stay here and die, family worried they would to go into hospital, resident didn't go as not in the best interest it was the resident wish. Staff to be able to challenge family re decisions.*
- *Making family feel make right discussion. Hard for person and family when they need to come into the home. Supporting resident but also supporting family as a hard decision to send someone to home when they have dementia. No-one can look after their loved ones like they can.*
- *Housing resident and family were really really happy with outcome and GP was here at the same time, talked through how it would go and GP agreed with me. Daughter glad she had support from someone like me. Another members' family said this person left some carers some money which was appreciated and made a big impact on me as it was not expected I was really shocked.*
- *Having privilege to know individual and families and support them in a way that they wish.*

5. **What would you change about the way that services are being integrated to improve care for your patients?**

It was felt that a number of factors should be considered to integrate services further, including:

Organisation:

- *To be more organised, planning things for residents, meetings to be booked services to let us know when they are coming. Four Patient Involvement residents in building as well as GP, dietitian and they all want answers to the question. I need time for them. Should be able to come anytime to the home to check the residents for their best interest. If coming at 2pm we are busy just like some notice so can be available. Change how inspect us make it more friendly rather than "going to eat you know".*
- *LA hubs they all take time. Can't speak to an individual. If I know doctor has been to see a patient I can't then get hold of them.*

Frequency of nurse visits:

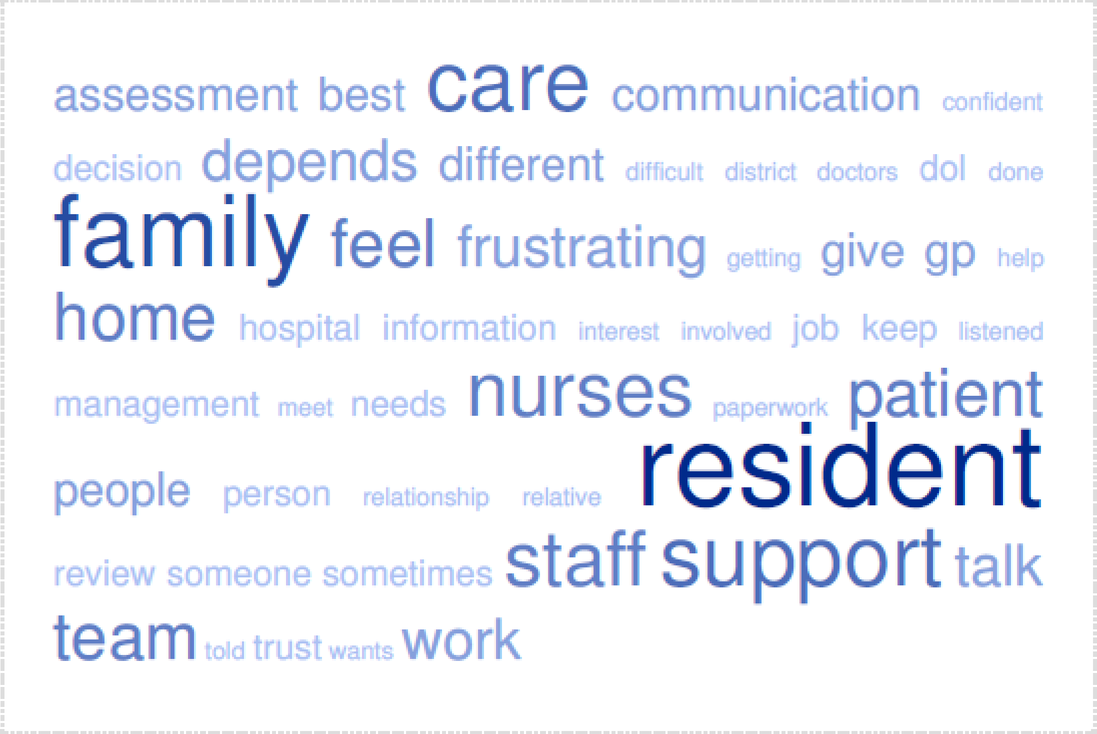
- *Getting nurses in more often – Nurses experts in dressings etc. is needed – Nurse availability.*
- *This is good so long as it's safe to do so. Make access to nurses easier.*

Communication:

- *All down to communications. If people say they are going to do it do it. Having a good support for the patient and staff. Open and honest assessment of the resident's needs. Limited assessment in hospital reading notes is difficult to make decision if not given enough info about the patient to assess whether they're right for the home (staff and other residents) Difficult to talk to the nurses and physios in the hospital. If residents need a continence assessment this should be started before they leave hospital.*
- *If systems talking to each other and all seeing same information.*
- *Direct contact with care givers.*
- *Wouldn't have them integrated, you lose continuity maybe. Sometimes when you do this you don't have consistency as departments change and can't track things down. I would change the communication with health professionals, dietitian problem they are just in the office don't come out anymore. Continuity, same dietician/ nurses each time or the same team. NHS lacks OT's and physios at the moment. They have personal touch and residents may open up and say different thing to them. Reassure my staff and residents.*

Integrated working:

- *Central hub to leave messages, so they can call us back.*
- *Single point of access, speak to call handler don't know if messages have been passed on.*
- *Join departments up.*
- *Have a conversation about situation instead of going through a scripted crib sheet would save time when trying to pass information on.*



(Key words used from care home and domiciliary care staff questions)

A summary of themes highlighted by care home and domiciliary staff:

The findings from this section demonstrate the key areas of high impact on care home and domiciliary care staff which need to be reviewed in order to deliver the best possible care for patients. It is apparent that staff feel very passionate about the care they deliver and the resources and support they subsequently require, furthermore the importance of integrated services, communication, involvement and team working is widely reported.

Many responses also suggest that emotional and physical support is an area of concern and that time factors sometimes prevent this to be considered but equally is as important as other areas listed.

9. Summary of report findings

- It was found that many emerging themes were interlinked across the various groups and were pertinent to patients, carers and staff. The research also highlighted the similarities and differences which contribute to delivering effective care to patients. Many themes were linked to communication methods, relationship building with families and staff and challenges within the current community services setting

- A high level literature review undertaken by Arden and GEM CSU demonstrates that the findings of this report concur with research undertaken by other organisations over the past 2 years.

- Many key themes were highlighted across the various cohorts and high impact areas are linked directly to each theme. These include:
    - Good communication
    - Relationship with families
    - Supported by a team
    - Partnership working
    - Satisfaction in the work staff deliver
    - Time factor
    - Involvement in making decisions
    - Staff recognition
    - Training for staff
    - Integrated working

- A summary of themes highlighted by carers include:
    - ➢ Family carers want services which are reliable and appropriate to their situation and allow them to support their loved one. They report difficulties in getting the help they need and frustration around processes, including decision making and the discharge process. Getting further help at times of crisis was a particular challenge for some.
    - ➢ Carers reported mixed relationships with services and staff. They did not always receive consistent information and were not involved and kept informed.
    - ➢ The caring role resulted in emotional stress for carers, such that they did not feel that they could take holidays or breaks.
    - ➢ Particular areas of concern were falls, getting help when their loved ones' health deteriorates, administering painkillers.

- A summary of themes highlighted by frontline staff include:
  - Building good relations and working together with patients and families is important to staff.
  - Time and workload pressures reduce their ability to develop a good relationship with patients and families.
  - Providing emotional support can be a very rewarding but more guidance, training and time are needed.
  - Relationships with other services significantly impact on the care given. The quality of these relationships currently varies but is improved where individuals know each other.
  - There can be issues between services around poor communication, lack of awareness of services or where a referral criterion is not clear or understood. Relations with Social Services can be a particular issue.
  - Staff suggest that IT support, in particular SystmOne, can support closer working between services, eg the referral process.
  - Job satisfaction is important to staff, they want to feel that their work is valued and they have made a difference to patients and their family. However, they report feeling stressed and tired, in particular where they are short staffed and there is a high caseload. The job is made easier by supportive colleagues and leaders who work well together, and good relationships with other teams exist.

- A summary of themes highlighted by patients in a community bed**:**
  - The importance of good communication throughout all stages of the patient journey resounds throughout and is essential for patients to feel confident, cared for and supported.
  - The need to feel supported is also essential to recovery, wellbeing and confidence and patients demonstrate their reliance on support not only while in hospital to aid successful recovery, particularly from physiotherapists, other hospital staff, friends and relatives but also when they return home.
  - There is also a strong sense of the impact of loneliness and social isolation before and after admission to hospital and patients talk about loss of confidence and there need for support.

- A summary of themes highlighted by people receiving care in a place they call home:
  - In general the picture relayed by patients in their own home is mixed. Patients would prefer to stay in their own home, but their level of confidence is dependent on support from family and external agencies which can vary.

  - Relations with services, including GPs are important. The inability to get timely appointments and to see the same GP, not arriving on time and lack of communication are all mentioned as issues. However, people feel that an improved relationship with health and care services would give them more confidence.
  - Falls and deteriorating health are frequently mentioned as a cause of crisis. Assistive technology can provide reassurance. Some service users will call family and use the 999 or NHS 111 services while others do not expect or seek help.
  - Patients can be left feeling stressed and lonely. They would like to do the things they were once able to do. Socialising, involvement in external agencies, keeping busy and physically active are used to reduce the emotional impact of their condition.

- A summary of themes highlighted by care home and domiciliary staff
  - Staff feel passionate about the care they deliver and the resources and support they subsequently require, furthermore the importance of integrated services, communication, involvement and team working is widely reported.
  - Emotional and physical support for staff is an area of concern. Staff explain that time factors sometimes prevent this to be considered.

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Overall, the findings of the report demonstrate the interdependency of health and social care services to meet the physical, mental, and emotional wellbeing of patients, carers and staff, in order to achieve a fully functioning integrated community health service capable of producing the best outcomes for all.