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Rutland

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Healthwatch Rutland Engagement Report: The NHS Long Term Plan

September
2019

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Summary

Background

The NHS Long Term Plan was published in January 2019. NHS England commissioned Healthwatch England to carry out public engagement in Spring 2019. As a result, Healthwatch Leicester and Leicestershire and Healthwatch Rutland (HWR) were asked to work together in completing this engagement across the whole of the Leicester, Leicestershire and Rutland (LLR) footprint. Although a report has been prepared for the whole of LLR, this report deals specifically with Rutland people's experiences, needs and expectations of their health and care services.

What we did

We promoted and distributed the 2 Healthwatch England surveys: one for the general population and one for those with long-term conditions. These were quantitatively analysed. We also collected patient's stories, carried out focus groups with young people and young adults with learning disabilities, autism or additional needs and semi-structured interviews with dementia patients and their carers. These, and free text replies in the surveys, were thematically analysed.

Key findings

Some of the key findings are a reinforcement of comments received by Healthwatch Rutland in previous engagements, but Rutland people have sent a clear message of what they want and need and what is not working well for them:

- Rutland people want more health and care services to be delivered locally and have easy access to them.
- People are frustrated by the delays and difficulties in getting GP appointments.
- There are anxiety-provoking breakdowns in communications between primary (GP) care and acute (hospital) care.
- Mental health patients are not satisfied with the speed and quality of the support they are offered.
- Rutland people want to be 'listened to' by the health and care professionals and want their interactions with them to be considered as a partnership relationship.
- Those with dementia and young people with learning disabilities and additional needs are at risk of being disadvantaged in health and care services due to digital exclusion.

- Carers are more concerned than non-carers about joint decision-making with professionals, convenient travel to access services and in having a say in how NHS money is spent for them if they have a long-term condition.

- There are mixed messages about community support and activities. Generally, women value this more than men.

- People want continuity of care.

Recommendations

- Better use of local facilities for more health and care services to be delivered in Rutland to avoid lengthy and difficult journeys out of the county.

- Public transport needs improvement to avoid inequities in accessing health and care facilities.

- Local surgeries should be helped to increase the availability of GP appointments.

- Communications, especially between primary and secondary care, need to be greatly improved.

- While advances in digital technology are welcomed by many, those who are digitally excluded need to be considered.

- The differing needs of Rutland males and females should not be overlooked when planning community and social support and activities.

- Professionals should recognise the value and occasional disbenefits of continuity of care for patients.

Context

Rutland is England's smallest county situated between Northamptonshire, Lincolnshire and Leicestershire. Oakham (the county town) and Uppingham are the only two towns and there are in excess of 40 villages.

There are General Practitioner surgeries in Oakham, Uppingham (with a satellite surgery in Barrowden), Market Overton and Somerby (a joined practice with the latter being in Leicestershire) and Empingham. Rutland residents who live near county borders may also choose to attend out-of-county GP surgeries in Stamford (Lincolnshire), Melton Mowbray (Leicestershire) and Corby (Northamptonshire). Rutland Memorial Hospital in Oakham hosts a minor injury and urgent care centre, outpatients' facilities and a rehabilitation ward.

There are no secondary, acute care hospital facilities in Rutland and people mostly choose to attend Leicester, Peterborough (Cambridgeshire), Kettering (Northamptonshire) and Grantham (Lincolnshire) for their acute hospital care.

Rutland is included in the East Leicestershire and Rutland Clinical Commissioning Group footprint. With the local authority areas of Leicester city and Leicestershire county, Rutland is also part of the Better Care Together[1] geographical area covering Leicester, Leicestershire and Rutland.

The Office for National Statistics (2019)[2] projections for the populations of Rutland, Leicester and Leicestershire follow:

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[1] Formerly known as the Sustainability and Transformation Partnership (STP)

[2] Retrieved from www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/localauthoritiesinenglandtable2

Age (years)	Rutland	Leicester	Leicestershire
0-14 years	6,300 16%	74,300 21%	117,300 17%
15 - 24	3,800 10%	62,500 17%	81,800 12%
20 -34	4,100 10%	59,700 17%	80,000 12%
35 - 44	4,300 11%	45,700 13%	81,000 12%
45 - 54	5,500 14%	39,100 11%	100,100 14%
55 - 64	5,300 14%	34,800 10%	90,400 13%
65 - 74	5,300 14%	24,300 7%	79,300 11%
75 +	4,700 12%	19,100 5%	65,500 9%
Total	39,300	359,500	695,400

Table 1. Population by age group across Rutland, Leicester and Leicestershire.

Rutland's 65+ age group constitutes 26% of its total population. This compares with 12% of Leicester's 65+ age group and 20% of Leicestershire's 65+ population. The national average for the 65+ percentage of the whole population is 18%. As the elderly, more than younger groups, generally present with more health problems, there is an immediate and, also projected, increased demand for health and social care facilities in Rutland.

The 2011 national census shows the population of Rutland then as 35,654 with a lower ethnic diversity than its neighbouring counties:

White	Asian	Mixed	Black	Other
97.1%	1%	1%	0.7%	0.2%

Table 2. The population by ethnic groups in Rutland. Source: Joint Strategic Needs Assessment, Rutland County Council (2018)[3]

The Rutland lack of ethnic diversity is in contrast to the multi-ethnic populations of Leicester and Leicestershire which are shown, for comparison, in the table below:

	White British	Indian	White other	Other ethnic groups
Leicester	45%	28%	5%	21%
Leicestershire	89%	4%	3%	4%

Table 3. The ethnic populations of Leicester and Leicestershire. Source: Jivraj and Finney (2013) The Centre on dynamic of Ethnicity, The University of Manchester[4].

The comparison of ethnic diversity is particularly relevant because different ethnic groups are more or less susceptible to different illnesses such as sickle cell anaemia, thalassaemia or diabetes.

A similar lack of diversity, compared with Leicester and Leicestershire, is reflected in religion and language as the tables in appendix 1 demonstrate.

Despite pockets of poverty, Rutland is generally considered to be affluent. In 2016 Rutland was the third least deprived upper tier authority area in the country.

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[3] Retrieved from: https://www.rutland.gov.uk/my-services/health-and-family/health-and-nhs/joint-strategic-needs-assessment/

[4] Retrieved from http://hummedia.manchester.ac.uk/institutes/code/briefings/localdynamicsofdiversity/geographies-of-diversity-in-leicestershire.pdf

Data Collection

A mixed methods approach was taken. We widely promoted the Healthwatch England 'general' survey for the whole population and the 'long-term conditions' survey for patients, their families and carers who are living with chronic illness[5]. Both of these surveys were made available online and via hard copies which we distributed around libraries, Rutland County Council offices, GP surgeries, churches and community hubs. Both surveys asked about people's past health and care experiences and hopes and expectations for future services. In all, there were 105 responses to the general survey and the participants' demographic details are shown in the following table:

Age (years)	**Female**	**Male**	**Not stated**	**Total**
Under 18	3	0		3
18-24	1	1		2
25-34	5	0		5
35-44	3	3		6
45-54	14	1		15
55-64	16	7		23
65-74	6	11		17
75+	18	10		28
No reply			6	6
Total	66	33	6	105

Table 4. Age and gender of general survey respondents

Consistent with the whole Rutland population, there was little ethnic and religious diversity among those taking part in the engagement but further demographic tables are in appendix 1.

48 people completed the long-term conditions survey: 27 female; 17 male; and 4 who did not state their gender. 37 respondents were aged 35 years and over; 9 were aged under 35

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[5] Throughout this report we define 'those living with' as patients, their families and carers.

years and two did not state their age. The breakdown according to conditions is shown in the following table:

Autism	5	10%
Cancer	9	19%
Dementia	9	19%
Heart/lung	2	4%
Learning disability	6	13%
Long term condition (unspecified)	11	23%
Mental health	6	13%
No reply	0	
Total	48	

Table 5. The breakdown of participants' long-term condition

To add extra richness to the results, we held focus groups and interviews with people who have been previously under-represented in survey responses; those with dementia and their carers and young people and young adults with learning disabilities, autism and additional needs and their carers. We also collected patients' stories about their experiences of encounters with the NHS.

The learning disabilities and additional needs focus groups met carers and young people and young adults aged up to 25 years who are:

A) on the autistic spectrum

B) living with a learning disability

C) living with a physical disability

D) living with mental health issues

All were attending the Rutland youth groups: Youth CHAOS, Disabled Youth Forum or the Out of Hours Club. In total, 62 people were engaged in these focus groups.

Contact with dementia groups was facilitated by Rutland Community Ventures and Age UK. Nine interviews with dementia patients and their carers ('duos') involved semi-structured, open-ended questions to encourage participants to talk freely about their experiences and health and social care needs. Interviews lasted between 30 and 90 minutes. A suggested list of questions was prepared (appendix 2) and resulted in rich details of the dementia journey.

We also drew themes out of five patients' stories about their experiences of the NHS. These had been either written by patients or verbally related to HWR personnel.

Taking part was entirely voluntary and people were told they could withdraw from the engagement if they wished. Signed, informed consent was obtained from all the participants in the focus groups and semi-structured interviews. Participants' complete confidentiality was guaranteed and all names stated in this report are pseudonyms. As the face-to-face engagement had a focus on vulnerable people, all HWR personnel were Disclosure and Barring Service (DBS) checked and aware of participants' possible vulnerabilities (physical and emotional). To deal with any resulting emotional responses, a debrief time was permitted for all participants, who were also given the contact details of lead HWR personnel in case they wished to discuss any resulting problems.

Prior to the interviews and focus groups, we also sought advice about the best approach from the local Admiral[6] nurse, a volunteer worker with dementia patients and a volunteer worker with young people and young adults with learning disabilities and/or autism and/or additional needs. As a result 'easy read' questions and visual aids were produced[7] for the focus groups and we were prepared to accept that dementia patients and their carers might want to talk in pairs rather than as part of a group.

The more long-term risk of this engagement for participants was the potential for the questions to be interpreted as an indication of immediate improvements which might not be delivered. Risks to HWR personnel included emotional responses and the team were made aware of the need for peer support during the project.

Data Analysis

The semi-structured interviews, focus group notes, free-text data in the general and long term conditions surveys and patient's stories were thematically analysed. The responses from the surveys were quantitatively analysed and further information was obtained by adding the variables of age, gender, carer status and disease as appropriate. The participants' variables of religion, language, ethnicity and sexual orientation were disregarded due to minimal diversity but the tables of numbers are in appendix 1.

Where percentages are shown in tables, they have been rounded to whole numbers so columns do not always add up to 100%. Due to small sample sizes, figures given should be treated as indications rather than statistically significant. Also, where applicable, as fewer respondents responded to the 'unimportant' and 'very unimportant' categories these responses have been grouped together as 'not important'.

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[6] Admiral nurses – specialist dementia nurses who give support to families living with dementia.

[7] The structure and questions for both groups are in appendix 2.

What people told us

By incorporating qualitative and quantitative data, we have been able to identify indications of what matters most for the Rutland population and for their health and care. The results will now be discussed thematically.

Accessing health and care services

Public transport is limited and infrequent in Rutland with, sometimes, inappropriately timed onward connections making access to health care facilities difficult, slow, tedious and lengthy; especially for the ill and disabled. Voluntary driver schemes exist at a cost for patients and Thames Ambulance Service provides door to door transport for eligible patients. In this section, responses relating to transport in both surveys and the dementia interviews are explored. The ramifications of transport difficulties mean that Rutland people want more care closer to home and want to be able to choose where they go for their health and care services.

We particularly compared Rutland responses in the general survey with those of Leicester and Leicestershire to get some indication of whether Rutland people feel they are being disadvantaged when accessing health and care services.

Respondents were asked to rate the following statement in order of importance:

'I want there to be convenient ways to travel to health and care services when I need to.'

	Rutland	**Leicester**	**Leicestershire**
Very important	74% (78)	60% (90)	64% (118)
Important	22% (23)	31% (47)	28% (52)
Neutral	3% (3)	7% (11)	4% (7)
Not important	0	0.6% (1)	2% (3)
No reply	0% (1)	0.6% (1)	2% (4)
Total	105	150	184

Table 6. The importance of convenient travel to patients with long-term conditions.

All respondents in all areas prioritised convenient travel, but a greater percentage of Rutland people (74%) rated it as 'very important' than their Leicester (60%) and Leicestershire counterparts (64%). The results also revealed that 80% of Rutland females, compared with 61% of males, said convenient travel was 'very important'. The Rutland lower importance rating of ‘neutral’ (3%) were from males, suggesting that females value convenient travel more highly than males.

The long-term conditions survey asked people in more detail about their willingness to travel (in terms of time) at various stages of their illness. As shown in the following two tables, we compared the Rutland responses with those of people from Leicester and Leicestershire.

How much time would you be willing to travel for to receive a quick and accurate diagnosis?

	Rutland	**Leicester**	**Leicestershire**
Less than 30 minutes	15% (7)	18% (4)	20% (18)
30 minutes - 1 hour	46% (22)	55% (12)	44% (39)
1-2 hours	21% (10)	23% (5)	19% (17)
More than 2 hours	10% (5)	4% (1)	17% (15)
No reply	8% (4)		
Total	48	22	89

Table 7. How much time people are willing to travel to receive a quick and accurate diagnosis.

Table 7 shows that Leicestershire people are more willing than Leicester or Rutland people to travel more than 2 hours to get a quick and accurate diagnosis and they were also the group most willing to travel less than 30 minutes. 63% of Leicestershire people said they were willing to travel from 30 minutes - 2 hours compared with the respondents from Rutland (67%) and Leicester (78%). Leicester people (4%) were the least willing to travel for more than 2 hours and the most willing to travel for 30 minutes - 1 hour.

How much time would you be willing to travel to receive specialist treatment or support?

	Rutland	**Leicester**	**Leicestershire**
Less than 30 minutes	8% (4)	9% (2)	17% (15)
30 minutes-1 hour	43% (21)	64 % (14)	43% (38)
1-2 hours	29% (14)	23% (5)	28% (25)
More than 2 hours	13% (6)	5% (1)	12% (11)
No reply	6% (3)		
Total	48	22	89

Table 8. How long people are prepared to travel for specialist care.

Whereas 43% of both Rutland and Leicestershire respondents said they were willing to travel for 30 minutes – 60 minutes to receive specialist care, 64% of Leicester respondents were prepared to travel for 30 - 60 minutes and were the least willing to travel for more than 2 hours. All three groups were prepared to travel for longer if they were going to see a specialist rather than to receive a quick and accurate diagnosis.

The wording of these last two questions could be accused of leading to a biased response in that people with long-term conditions are most likely to know and have experience of journey times to their nearest health and care services (for diagnosis and for specialist care) and have reflected this knowledge in their responses. However, what is clear from tables 6 and 7 is that people want health and care services to be local and accessible with no journey taking more than 2 hours. Those living closer to the city hospitals are the least willing to make lengthy journeys and this probably reflects their greater proximity to these facilities. Journeys from Rutland villages by public transport can often take 2 hours or more. The journey from some parts of Rutland to Leicester Royal Infirmary by car takes upwards of 90 minutes at peak travel and hospital car parking times.

To further confirm the hypothesis that Rutland people find public transport to health and care services more difficult, the main means of transport for the long-term conditions across Leicester, Leicestershire and Rutland was compared:

What is your main means of transport?

	Rutland	**Leicester**	**Leicestershire**
Own car	71% (34)	24% (8)	51% (45)
Another's car	21% (10)	38% (5)	25% (22)
Train	2% (1)	5% (1)	2% (2)
Bus	2% (1)	14% (3)	16% (14)
Taxi	(0)	10% (2)	1% (1)
Other	2% (1)	10% (2)	6% (5)
No reply	2% (1)		
Total	48	21	89

Table 9. The main means of transport for people living with long-term conditions

The table above demonstrates that 92% of Rutland people living with long-term conditions depend on their own car or that of another as their main means of transport. This is compared with 62% of Leicester people and 76% of the Leicestershire population. Only 4% of Rutland people declared public transport (bus or train) as their main means of transport compared with 24% of the Leicester population and 18% of those living in Leicestershire.

71% of Rutland people living with a long-term condition have their own car, compared with 24% in Leicester and 51% in Leicestershire. These figures might be influenced by other factors such as age or affordability but they could also point to a need for and a greater dependence of Rutland people on a car due to a poor public transport infrastructure.

Comments about travel difficulties also featured in the Rutland general survey free text, with no respondent suggesting that travel is convenient:

> *"My surgery has recently merged with two others and appointments are not always held at the same buildings. This can be confusing for older people and very difficult for outlying villages without a bus service (even with a bus service an appointment must keep to bus timetable both to doctor and return home – not always possible if a delay or appointment does not coincide with timetables)."*
>
> *"I can't get a direct bus from Edith Weston to Oakham at present unable to access professional help after 5pm on a weekday."*

Although the majority of respondents were prepared to travel for 60 minutes or less, HWR consistently hears from Rutland people about the lengthy and difficult journeys to receive health and care support, as Ella, almost 80 and a carer for her husband who has dementia, said when she was thinking about her own transport issues:

> *"I don't think I will tackle Leicester Royal Infirmary again but I would drive to Leicester General or Peterborough and Oakham hospital. I know where to go. I've done the Royal lots of times, I would do it now but I would be reluctant. I would use a volunteer driver or a neighbour."*

John, a dementia patient spoke about the sense of loss he still experiences about no longer being able to drive and his difficulties with public transport:

> *"I can only travel anywhere with support either to guide me on public transport or to drive me there. I am therefore dependent on someone else being available to take me."*

Given the difficulties of using public transport to access secondary care and the high dependence on cars, it is, arguably, not surprising that 89% of respondents in the general survey stated that the ability to decide where to go for treatment was important or very important:

‘I make the decision about where to go to receive health and care support’

	Male	Female	Gender not stated	Total
Very Important	14 (42%)	39 (59%)	4 (66%)	57 (54%)
Important	14 (42%)	22 (33%)	1 (17%)	37 (35%)
Neutral	4 (12%)	5 (8%)	1 (17%)	10 (10%)
Not important	1 (3%)			1 (1%)
Total	33	66	6	105

Table 10. The importance of choice for general survey respondents in choosing where to receive health and care support (General survey)

The free text comments invited in the general survey further reflect the need Rutland people feel to have more services closer to home:

If there was one more thing that would help you manage and choose how the NHS supports you, what would it be?

“Remove the ‘POST CODE LOTTERY’. I can choose where I go to work. I have little or no choice if, where or when I receive treatment.”

“More hospital services at Rutland Memorial Hospital.”

This desire to have services closer to home was also a dominant theme in the following long-term conditions free text comments:

“The service in Rutland is dreadful and non-existent compared to [the] help the people get in the cities. [We ought] to have a mental health base In Oakham.” (mental health)

“We struggled to get anybody to listen to us and then when we finally had a referral from the GP we had to go to Leicester.” (dementia)

“[We need] services local to Rutland as opposed to the hospital referred to in Leicester.” (learning disabilities)

“Most support was within Leicester City and Leicestershire. Rutland seemed to be an inconvenient add-on.” (learning disabilities)

“If consultants held local clinics rather than patients having to "trek" miles to see them at their hospital or clinic. In my case it's at least 50 miles round trip to Leicester.” (heart and lung)

Patients' stories echoed this wish for services closer to home but with an added frustration for those who were told they must return to city hospitals for procedures which they considered could have been carried out by community nurses or GP surgeries.

These stories included details about a man who had to travel to Leicester Royal Infirmary haematology outpatients from a Rutland village just to be told his blood results were normal and he was being discharged. He questioned why these results could not have been given to him electronically, by letter or by phone or why the results cannot be made available to his GP, as happens with laboratory test results requested by local practices.

An elderly lady told us she had an outpatient dermatology procedure carried out to her satisfaction by a specialist in Melton Mowbray hospital. She was then told she must travel to Leicester Royal Infirmary for the specialist to change her dressing. With great difficulty she attended the appointment where her dressing was changed by an unsupervised student nurse. She did not see the specialist. The dressing fell off within a few hours of her return home. She contacted her local surgery and the dressing was replaced locally.

A blind man in his late 80s was told he needed to return to Leicester General Hospital to have his urinary catheter removed. At his wife's protest, this was done by a community nurse.

Therefore, more care, closer to home remains a priority for many Rutland people. The General Practitioner surgeries are, of course, closer to home so we next turn to the themes emerging from the engagement about these services.

Section summary

- Convenient travel to access health and care is rated 'very important' by more Rutland people (76%) than Leicester (60%) and Leicestershire people (64%).
- Leicester people (4%) are less willing to spend more than 2 hours travelling for a quick and accurate diagnosis than Rutland people (10%) and Leicestershire people (17%).
- All respondents are prepared to travel for slightly longer if they are to receive specialist care.
- 92% of Rutland respondents are dependent on their own car or another's car as their main means of transport compared with 62% of Leicester city respondents and 76% Leicestershire respondents.
- 92% females and 84% males in Rutland rate being able to make the decision about where to access health and care services as 'very important' or 'important'.

Access to GP appointments

In common with most of the country, Rutland people are now experiencing longer delays than previously in getting GP appointments for non-urgent problems[8]. The general survey asked the question below and the respondents' replies are show in the chart:

How important to you is: 'Access to the help and treatment I need when I want it?'

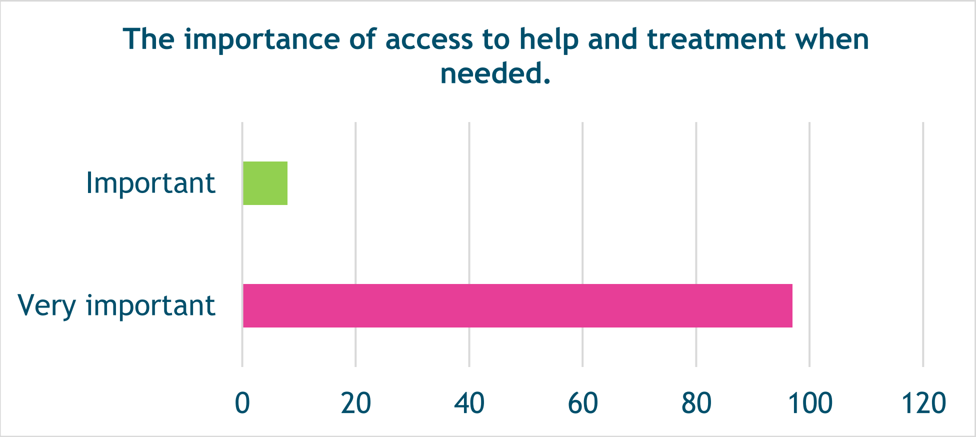

Chart 1. The importance of access to care - General Survey

There was unanimous agreement in the general survey that access when needed is 'very important' or 'important'. This was frequently repeated in the general survey free text comments and, more specifically, about difficulties in getting a GP appointment as the following examples demonstrate.

If there was one more thing that would help you live a healthy life, what would it be?

"Shorter waiting times for doctors' appointments."

"Easier access to GP appointments."

"More available doctors' appointments. There is a choice of appointments online but they get booked up quickly

"To have an appointment with the doctor of my choice on request day and NOT WAIT 2-3 WEEKS."

"More being able to get an appointment with GP when you need it, i.e. within 2 days, not in 2 weeks' time which is how it actually is."

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[8] See for example, BBC Panorama 'GPs: Why can't I get an appointment?' Retrieved from: https://www.bbc.co.uk/programmes/m0004wd7

How important to you is the statement, 'I can make appointments online and my options are not limited'

Being able to get an appointment online was identified as 'very important' (53%) or 'important' (28%) by 81% of people. However, 5% said it was 'not important', more than for other questions asked, indicating that this was less important to people overall.

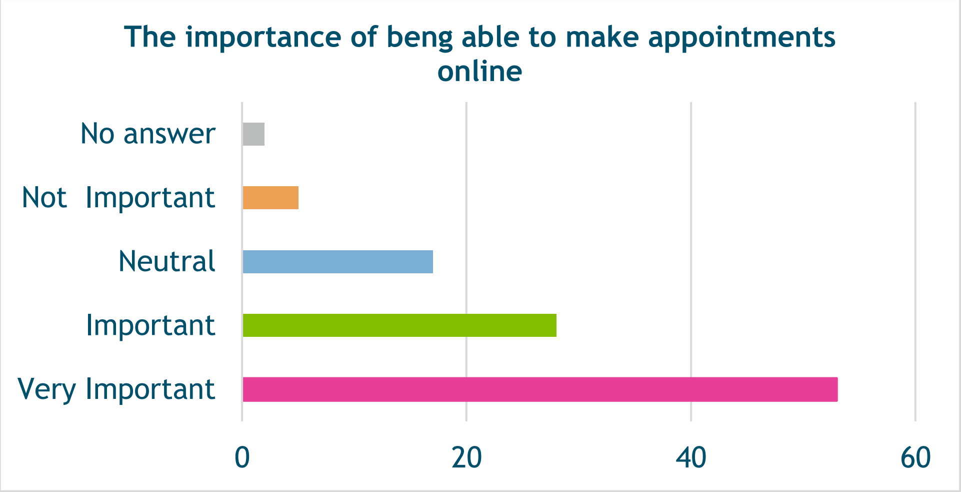

Chart 2. The importance of being able to make appointments online - General Survey

Additionally, the survey results highlighted ongoing problems in the communications between GP (primary) care and the professionals in acute hospital wards and departments (secondary care). This is explored in the following section.

Section summary

- There was unanimous agreement that access to help and treatment when needed is either 'very important" (92%) or 'important (8%)
- Free text comments indicate a difficulty in getting GP appointments
- Being able to book appointments online is considered 'very important' or 'important' by 81% of respondents.

The interface between GP and acute hospitals

The respondents frequently identified communication problems at the interface between primary and secondary care. The long-term condition respondents' experiences of the time from GP referral to seeing a specialist is shown below:

How would you describe the time you had to wait between your initial assessment /diagnosis and receiving treatment?

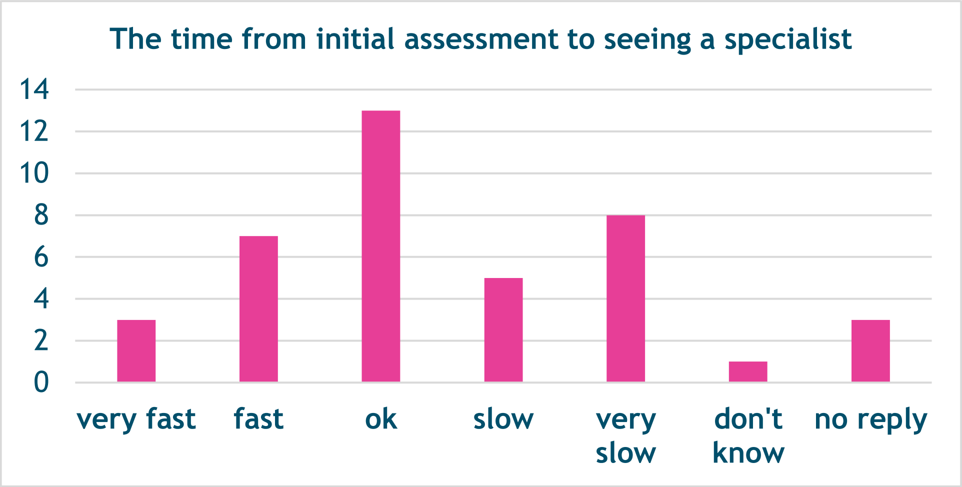

Chart 3. The respondents' assessment of time between initial assessment and seeing a specialist

Although 13 people said the time waiting to see a specialist was 'ok', 10 people rated it as 'very fast' or 'fast' and 13 respondents rated this time as 'slow' or 'very slow'. The combined Rutland, Leicester and Leicestershire figures clearly showed that cancer patients experienced the fastest service and those with mental health conditions received the slowest. So we explored the data further to understand whether this pattern was repeated in Rutland.

How would you describe the time you had to wait between initial appointment and seeing the specialist?

Cancer	Leicester, Leicestershire and Rutland	Rutland
Very fast or fast	8 (38%)	5 (56%)
Ok	4 (19%)	1 (1%)
Slow or very slow	5 (24%)	2 (22%)
No reply	4 (19%)	1 (11%)

Table 11 Cancer patients' rating of time they waited to see a specialist

Mental Health	Leicester, Leicestershire and Rutland	Rutland
Very fast or fast	3 (6%)	0
Ok	7 (13%)	1 (17%)
Slow or very slow	25 (47%)	4 (67%)
No reply	17 (32%)	1 (17%)

Table 12. Mental health patients rating of time they waited to see a specialist

Although the numbers are small when considering Rutland patients alone, the indications are that Rutland patients with mental health conditions wait longer than patients with cancer to see a specialist as is the case for the Leicester, Leicestershire and Rutland whole area.

How would you describe your overall experience of getting help?

In replying to the question asking about the quality of their overall experience of care, of the 6 Rutland residents with mental health conditions, 5 said they rated their experiences as ‘very negative’ (3) or ‘negative’ (2). Conversely, those with cancer seem to have received a much better experience with 6 out of 9 saying their experiences were ‘very positive’ (5) or ‘positive (1). Only one cancer respondent rated his or her experience as ‘negative’ and there were no ‘very negative’ results. These results are shown in the table below and confirm that the combined Leicester, Leicestershire and Rutland findings are reflected in Rutland. Cancer patients are more satisfied with their service and mental health patients receive a slow service and are the most dissatisfied.

	Very positive or positive	Average	Negative or very negative	No Comment
Cancer	6 (67%)	1 (11%)	1 (11%)	1 (11%)
Mental Illness	1 (17%)		5 (83%)	

Table 13. Discrepancies between Rutland cancer and mental health care satisfaction rates

The focus group report for young people and young adults with learning disabilities and/or additional needs also reflects difficulties in accessing specialist care:

> *"Young people living with multiple diagnoses of physical and learning disability and mental health issues experience a feeling of being shifted from one healthcare professional and healthcare site to another, often for the same condition; sometimes up to seven professionals just for one condition. This causes them to lose confidence in both the system and that they will be dealt with adequately. In some cases this leads to them disengaging completely and causes a sense of hopelessness which exacerbates their sense of isolation."*

Likewise, the dementia duos spoke of difficulties at the interface between primary and secondary care:

> *"It would be better if we knew who should be managing Mum - the GP or a consultant. She has been taking the tablets for three years, but nobody reviews her. We seem to be just gliding along."*
>
> *"Peterborough Hospital and Oakham Surgery systems are not compatible. A software problem meant that results and referral information between surgery and memory clinic had to be chased by GP. Also, in August last year after a fall, it took until Feb this year to get an appointment at the Falls clinic as the referral was not passed from GP to hospital."*

The long-term conditions survey invited free text comments. These also contain comments referring to communication problems:

> *"GP could have been more understanding/supportive and offer further tests or referral."*
>
> *"Did not take symptoms and issues seriously. Continually fobbed off. Waiting times to see consultants ridiculous."*

“My GP was not able to order an MRI scan so I had to see a Consultant first. This meant 3 hospital visits: 1st Consultant appt. Scan Appt at different hospital and another waiting list. Then result appointment. Process started in Feb. Final result Sept all the time was symptomatic with MS - very stressful long-term condition.”

“My GP understood my condition and was excellent it was at the hospital stage things slowed down because of lack of experience of junior doctors. Once I got to a consultant everything was OK.”

“The problem was the exchange of information between Peterborough City Hospital and Oakham GP Surgery.”

“With the involvement of so many different specialist disciplines (Oncology, ENT, Radiology, Haematology, Dentistry, Nutrition, etc.), it was sometimes up to me to ensure that they all communicated properly with each other - otherwise things would fall between the cracks. Intra-NHS communication isn't all that good.”

“Lack of communications between Trusts regarding patient notes. Having appointments outside the "local" Trust involves going back to basics and "starting again" not only with consultations but tests also, because one Trust doesn't want to rely on another Trust's previous outcomes... waste of NHS appointment time and money.”

Finally, free text responses to the following question in the general survey followed the same pattern:

If there was one more thing that would help you manage and choose how the NHS supports you, what would it be?’

“An end to this waiting for results... waiting for letters... waiting for appointments. Use of phone or e-mail instead of all these.”

“Better liaison across CCG [Clinical Commissioning Group] boundaries.”

“Ensure there are full, proper and prompt communication between ALL AREAS of NHS Care.”

The free texts comments shown above also have an extra nuance – that of patients and their families feeling a sense of loss of control within the complexities of the NHS. This is explored further in the next section.

Section summary

- Communications between primary and secondary care are commonly understood as being very problematical.
- There were mixed reports about the waiting time between first seeking help and seeing a specialist with cancer patients receiving the fastest referrals and people with mental health conditions receiving the slowest.
- 67% of cancer patients had a ‘positive’ or ‘very positive’ and 11% had a ‘negative’ or ‘very negative’ overall experience of getting help.
- 17% patients with mental health conditions had a ‘very positive’ or ‘positive’ and 83% had a ‘negative’ or ‘very negative’ overall experience of getting help.
- The discrepancies in care experiences between cancer patients and mental health patients are common across Rutland, Leicester and Leicestershire.

Patient choice and control?

Patients' sense of choice, control and joint partnership with the healthcare professionals is explored in both surveys. The general survey asked the following question and table 14 shows the responses.

What's most important to you to be able to manage and choose the support you need?

	Very important or important	Neutral	Unimportant	Not stated	Total
Professionals that listen to me when I speak about my concerns	102 (97%)	2 (2%)	0	1 (1%)	105
If I have a long-term condition, I decide how the NHS spends money on me	83 (79%)	18 (17%)	0	4 (4%)	105
Choosing the right treatment is a joint decision between me and the relevant health and care professional	104 (99%)	1 (1%)	0	0	105
I make the decision about where to go to receive health and care support	94 (90%)	10 (10%)	1 (1%)	0	105
I make the decision about when I will receive health and care support	85 (81%)	16 (15%)	1 (1%)	3 (3%)	105
My opinion on what is best for me, counts	86 (82%)	18 (17%)	0	1 (1%)	105
I have time to consider my options and make choices that are right for me	98 (93%)	7 (7%)	0	0	105

Table 14. The importance of autonomy for patients

As 14 shows, slightly less importance was accorded to deciding how NHS money is spent in the event of having a long-term condition, being able to decide when to receive health and care support and having an opinion about what is best for oneself. 97% of respondents in the general survey felt it is important or very important to have confidence that professionals listen to them and 99% saw decision-making about their health care as a joint exercise with the professionals. Respondents clearly want their interactions with the NHS to be understood as a 'partnership' of patient and professional working together. This was further elaborated in the free text:

If there was one more thing that would help you manage and choose how the NHS supports you, what would it be?

> *"Clearly communicate the options, the advantages and disadvantages of each option, work with me to get the best option for ME not putting me into THEIR system because it works for them."*

However, not all were in agreement as another respondent replied:

> *"I let the NHS make the decisions about my care. I have no complaints and consider that we are lucky to have such a caring organisation."*

But younger respondents with learning disabilities and additional needs experience greater anxiety with a sense of not knowing and others being in control. The focus group report states:

> *"Hospital appointments are highlighted as the worse for this [extra anxiety], as 'they will find something wrong' and 'having to wait ages and not knowing'. Young people with additional needs already experience higher levels of stress and anxiety from having to try harder to do basic tasks day-to-day. This added anxiety and a need to be 'ready for any outcome' only stresses them out more; leaving them with the jaded feeling of somebody else being in charge again."*

As one young person with learning disabilities wrote in the free text survey option:

> *"I did not know what to expect so did not know if what I was getting was good or bad."*

However, as the following comments from people with long term conditions demonstrate, patients want acceptance and understanding of their needs on the one hand, but, on the other, they want professionals and the wider society to help them live life as fully as possible.

“Work with me to help me integrate the medical care I need into my ‘normal’ life. I have a life-limiting condition but I want to live the life I have, not spend all my time waiting for medical care of one sort or another.” (cancer patient)

“Stop writing me off. I want and need a proactive health service that provides me with the skills, understanding and support to achieve a good quality of life at whatever stage of dementia I am at. A dementia diagnosis should not be met by a 'sit in that armchair and die' prescription.”

“I have learning disability, Down's syndrome, Autism and no speech with strangers so will need someone that signs if my mum or brother is not with me. I need time to process information, I need time to be able to use my communication aid.”

This section, referring to the relevance of knowledge, information and communications, leads to the following section and the respondents’ use of information and communications technology (ICT) in their interactions with the NHS.

Section summary

- Patients want to be seen as partners with the medical professionals in managing their care.
- Patients want professionals to listen to them when they express their concerns.
- Respondents were least concerned about how the NHS would spend money on them if they developed a long-term condition.
- Young people with learning disabilities find hospital appointments particularly stressful and disempowering.
- People with long-term conditions want support to be able to live their lives to the full and not be ‘written off’.

The NHS and Information and Communications Technology (ICT)

The Long Term Plan (2019) places emphasis on greater use of ICT to improve NHS productivity and efficiency and, thereby, increased convenience for patients. The general survey asked Rutland respondents to rate the importance in several questions about ICT usage as shown below:

	Data security	Ability to access services by phone or computer	Ability to manage own records
Very important	64 (61%)	53 (50%)	36 (34%)
Important	24 (23%)	35 (33%)	40 (38%)
Neutral	15 (14%)	14 (13%)	22 (21%)
Not important	1 (1%)	3 (3%)	6 (6%)
Not stated	1 (1%)		1 (1%)
Total	105	105	105

Table 15. The importance of different aspects of ICT usage in the NHS – Rutland responses

Therefore, the majority of respondents are prepared to use ICT. There is, though, slightly less enthusiasm for managing personal records. A further general survey question also revealed that 96% of respondents want their test results communicated quickly to them but this did not refer to the use of ICT.

The results in table 15 were then compared with those from Leicester and Leicestershire:

Leicester	Data security	Ability to access services by phone or computer	Ability to manage own records
Very important	89 (59%)	65 (45%)	58 (39%)
Important	41 (27%)	65 (45%)	55 (37%)
Neutral	16 (11%)	14 (9%)	32 (21%)
Not important	1 (1%)	4 (3%)	4 (3%)
Not stated	3 (4%)	2 (1%)	1 (1%)
Total	150	150	150

Table 16. The importance of different aspects of ICT usage in the NHS - Leicester

Leicestershire	**Data security**	**Ability to access services by phone or computer**	**Ability to manage own records**
Very important	105 (57%)	86 (47%)	68 (37%)
Important	50 (27%)	59 (32%)	64 (35%)
Neutral	23 (13%)	29 (16%)	45 (25%)
Not important	2 (1%)	7 (4%)	4 (2%)
Not stated	4 (2%)	3 (1%)	3 (2%)
Total	184	184	18

Table 17. The importance of different aspects of ICT usage in the NHS - Leicestershire

The data throws up some conundrums. Slightly more Rutland people (61%) rated data security as 'very important' than people from Leicester (59%) and Leicestershire (57%). Rutland people (50%) also rated the ability to access services by phone or computer as 'very important' - more than Leicester (45%) and Leicestershire (47%) people. However, Leicester (39%) and Leicestershire (37%) people rated the ability to manage their own records more highly than Rutland people (34%).

When 'very important' and 'important' ratings are combined the results are as follows:

	Rutland	**Leicester**	**Leicestershire**
Data security	84%	86%	84%
Access by phone or computer	83%	90%	79%
Manage own records	72%	76%	72%

Table18. Comparing Rutland, Leicester and Leicestershire average response rates for ratings of 'very important' and 'important'

Table 18 therefore shows that a higher percentage of Leicester people rated the use of computer and telephone, data security and managing their own records as 'very important' and 'important' than those in Rutland and Leicestershire. This could be attributed to the younger and more 'computer-savvy' Leicester demography. Rutland and Leicestershire respondents equally rated data security and managing records. Leicestershire people (79%) were the smallest group to rate access to services by phone or computer as 'very important' or 'important', which was again more important to Leicester people.

However, the focus group work and dementia patients' interviews highlight the fact that there are people who are digitally excluded. As a learning disabilities volunteer worker wrote:

> *"Technology – most can use a phone to make and receive calls, less use it for texts and even less uses their phone/tablet or computer to browse the internet. However three quarters of the group has an email address."*

We asked the dementia duos whether they are using technology and if so, how they were using it and what advantages they were finding. Responses specifically about computers included:

> *"No, basically I don't [use a computer]. I could switch it on and find my way around for basic information [....] but I haven't used it from one week to another. I prefer to telephone and talk to someone."*
>
> *"I used to be very computer literate when I was working and used it all the time for everything. I don't have the interest to use it anymore and can't use the 'phone easily due to my hearing loss - prefer to discuss my health face-to-face."*
>
> *"I am registered blind because of my dementia. I cannot read. I cannot type well. I struggle to use new technology. I can use my mobile to phone my wife."*

However, other technological innovations are of greater value for carers in ensuring the patients are safe, as the dementia group comments reveal:

> *"We did think about using Alexa [Amazon Echo] to remind Mum but somebody told us it would muddle her up even more. We are interested in Hive but have not really looked into it. That might be for the future."*
>
> *"If I go out, say, in the morning, I leave her in bed with a note beside the bed about where I am going and with my mobile phone number on it. It's no use telling her because she won't remember."*
>
> *"A wrist-strap panic alarm that Mum can press to alert call centre if she has fallen".*
>
> *"They can speak to mum via a loudspeaker in the house and if there is no response they call [up to 3] family members and if no reply they call an ambulance. It gives mum and us peace of mind and was suggested by the occupational therapist. We got a 3 month free trial and now pay £80 per year for the service."*
>
> *"Panic alarm gives me peace of mind - and my key safe."*

Therefore, technological advances in accessing services within the NHS are broadly accepted but there remain those who are unable to access ICT. It was, though, the carers' comments that prompted a specific search through the data for more detail about their experiences, the results of which are set out in the following section.

Section summary

- The majority of Rutland people rate the use of ICT as 'very important' or 'important'.
- Fewer Rutland people rate managing their own records as 'very important' or 'important'.
- A comparison across the region shows that slightly higher percentage of Leicester people are a likely to rate aspects of the use of ICT for healthcare purposes as 'very important' or 'important' than those in Leicestershire and Rutland.
- People with dementia and young people and young adults with learning disabilities and/or additional needs are likely to be digitally excluded.

Carers’ experiences and expectations of the NHS

The Long Term Plan focusses on people remaining at home for as long as possible and the avoidance of emergency admissions to acute hospitals. In the general survey the greatest number of people, 81%, rated ‘staying at home for as long as it is safe’ as ‘very important’ and 17% rated this as ‘important’. It therefore follows that the provision of care in the home is also very important. Carers’ opinions and needs therefore must also be taken into account. This section looks at those results which revealed marked discrepancies between carers and non-carers in Rutland. Both the general survey and the long-term conditions asked respondents if they are carers and the results are shown in the following table:

	General survey		Long-term conditions survey	
	Female	**Male**	**Female**	**Male**
Under 18	1			
18 - 24				
25 - 34	2		3	
35 - 44	1			
45 - 54	3		2	
55 - 64	4		1	
65 - 74		1	1	
75+	1		1	1
Total	**12**	**1**	**8**	**1**

Table 19. Self-identified carers, their age and gender in general survey and long-term conditions survey

With such a small sample, results in this section can, at best, be understood as an indication and not statistically significant but they do present an opportunity to consider carrying out further and more extensive research into the carer role in Rutland and beyond. Only 2 of 22 people who self-identified as carers were male, indicating that either the carer role in Rutland is predominantly taken up by females or that male carers are less likely to complete surveys; the latter being more likely as the general survey was completed by twice as many females than males. The highest number of carers in the general survey fall into the 55-64 years age group. In the long-term condition survey, the highest number of carers are aged 25-34 years

The questions in the two surveys differed so it is not possible to amalgamate the two sets of responses to form a conclusion. From the general survey we noted the following notable discrepancies between non-carer and carer responses:

- More non-carers (94%) than carers (77%) rated ‘access to the help and treatment I need when I want it’ as very important.
- More non-carers (89%) than carers (77%) rated ‘I want professionals that listen to me when I speak about my concerns’ as ‘very important’.

But, conversely, a marked higher percentage of carers than non-carers rated the following aspects as ‘very important’:

- Wanting convenient ways to travel to health and care services when needed (carers 92%, non-carers 72%).
- Deciding how the NHS spends money on them if they have a long term condition (carers 54%, non carers 39%).
- Choosing the right treatments is a joint decision between the carer and the relevant health and care professional (carers 85%, non-carers 69%).
- Being offered care and support in other areas if they can’t be seen locally in a timely way (carers 69%, non-carers 52%).
- Carers (61%) and non-carers (50%) rated ‘my opinion on what is best for me counts’ as very important

In addition, 100% of carers compared with 87% of non-carers, rated ‘being able to make the decision about where to go for treatment as ‘very important’ or ‘important’.

So, although carers seem to be more relaxed about a listening approach from professionals, they are less so about the practicalities of care such as transport, finances and joint decision making with the professionals. This may be because carers have had greater experience of the NHS services, have experienced difficulties and can see where improvements are needed resulting in them being somewhat inured to difficulties such as ‘non-listening’ professionals when encountering NHS services.

Although the medications had not featured in the list of suggested questions for the dementia interviews, several carers referred to the difficulties they experienced in getting, storing and administering prescribed drugs, as follows:

“You don’t realise how much is involved in caring for someone with dementia until you’re in the hot seat. She won’t take her tablets. She’s got lots of health problems. Sometimes I give them to her and find that she’s been hiding them. Then I get cross because it’s making my job harder. Dr. X cut some of them out but she still gets tired from the drugs.”

“Only one drug was able to be prescribed because of his other health problems. This drug was delivered monthly from Oadby [to our home in Oakham]. He started with a 20mg dose and it seemed to help.”

“She has been taking the tablets for three years but nobody reviews her.”

“Currently have a problem with B12 injections that were prescribed 3 monthly after mum was diagnosed with deficiency in August last year. The District Nurse put injections in the fridge and brought a disposal bucket but we have no idea if any have been administered and have been told we now have to organise it ourselves.”

Tiny’s story[9] about being a carer for his terminally ill wife drew our attention to the problems associated with polypharmacy (the use of many different medications). His wife was given drugs for one condition, which, in turn, caused side effects for which other drugs were prescribed. He also told us of his concerns that, with multiple drugs in the house, they might be burgled for the black-market value of the opiates they were storing.

Medication concerns were also raised in the focus groups for young people with learning disabilities and other needs as the report states:

“Young people on different medication for different conditions often lose track of what they are taking and why. They are often dependent on their carer to ensure they take the right quantity and at the right times.”

In the next section the focus is on how age and gender influences people’s approaches to health and care services and how care in the community is perceived and what improvements might be wanted.

Section summary

- The results indicate that, in Rutland, most carers are female and in the 55-64 age group.
- There are more carers in the 25-34 age group than in any other age group for people with long-term conditions.
- Medication management is an added and difficult responsibility for carers.
- More non-carers than carers rate access to health services and professionals that listen to them as ‘very important’.
- Carers rate the following more highly than non-carers:
  1. Convenient travel
  2. Saying how NHS money should be spent on their care
  3. Joint decision making with health professionals
  4. Their own opinion counts
  5. Out of area care if local services are not readily available

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[9] The full report on Tiny and Evie’s story can be seen in appendix 3

Community and the personal implications of illness and care

Age and gender are, arguably, major influences on how the social world is experienced both in daily lives and in terms of illness and health. For example, 66 females compared with 33 males (+6 no gender specified) completed the general survey. As mentioned in the previous section, this could be attributed to several influences not least that females might be more prepared than males to fill in surveys or females are more engaged with health and care services. As table 4 demonstrates, there was a higher response rate from older people than the younger age groups. We explored the data for marked discrepancies in the survey responses between gender and age and some results are shown below:

For every interaction with health and care services to count; my time is valued

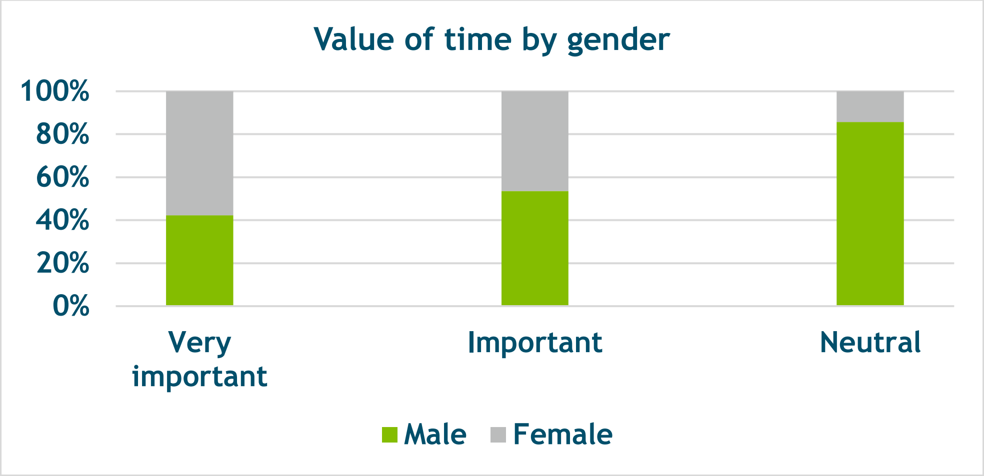

Chart 4. The value of time by gender

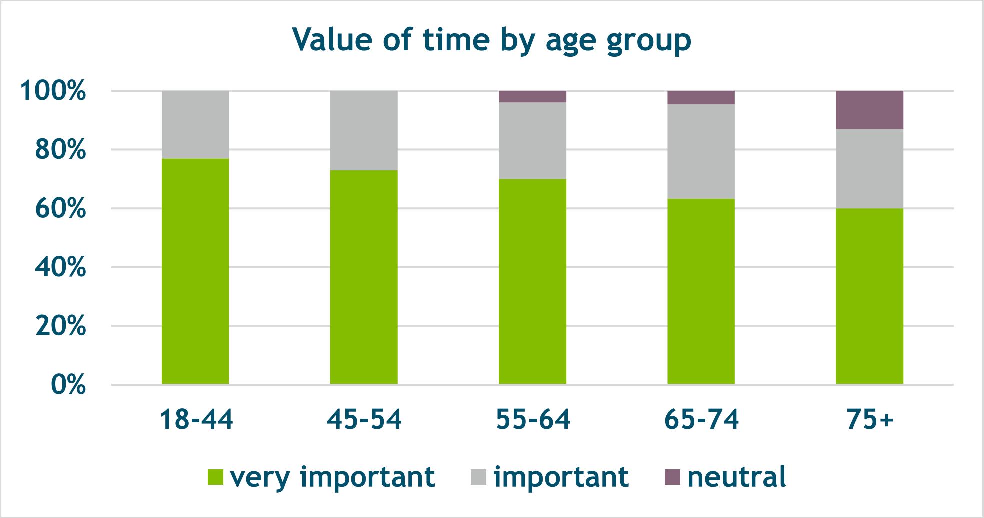

Chart 5. The value of time by age group

Charts 4 and 5 demonstrate that more females than males want their time to be valued. Also older generations place less value on their time spent dealing with the NHS than younger generations. Possible explanation for these age discrepancies include the suggestion that older people are retired or semi-retired and their time is more expendable or, given their higher disease burden, they might be more inured to the delays in NHS waiting and consulting rooms.

We then noted further discrepancies between the genders:

How important to you is the statement, ‘My opinion on what is best for me, counts’?

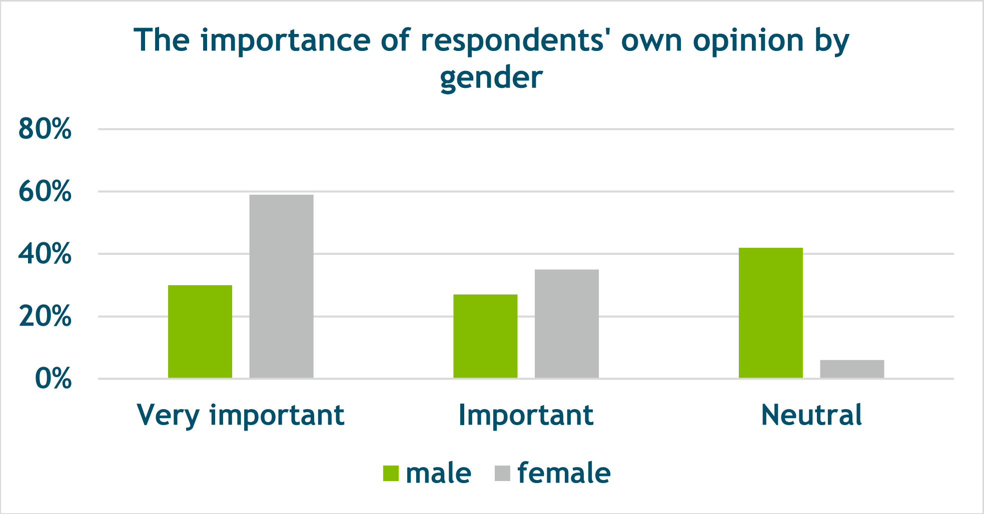

Chart 6. The importance of having an opinion that counts - by gender

Chart 6 adds some credibility to the earlier suggestion that women, more than men, are actively involved in health and care services and are more likely to want their opinions heard and respected.

Although there was no discernible pattern across the age groups, but with women placing greater importance on their own opinions being valued in chart 6, we looked further at the data pertinent to autonomy and found the following marked discrepancies:

- 88% females and 60% males rated ‘very important’ or ‘important’ being able to choose how the NHS spends money on them if they have a long-term condition.
- 87% females and 69% men rated ‘very important’ or ‘important’ being able to make the decision about when they receive health and care support.
- 97% females and 85% males rated having time to make decisions as ‘very important’ or important’.

We also added the variables of age and gender to better understand how people value community support. Table 20 shows that more females (61%) than males (33%) rated having community support as ‘very important’. 88% females rated community support as ‘very important’ or ‘important’ compared with 69% males. 27% males and 12% females said they were ‘neutral’ about the importance of community support.

I want my community to be able to support me to live my life the way I want:

	Male	Female	Not stated	Total
Very important	11 (33%)	40 (61%)	5	56 (33%)
Important	12 (36%)	18 (27%)	1	31 (30%)
Neutral	9 (27%)	8 (12%)		17 (17%)
Not important	1 (3%)			1 (1%)
Total	33	66	6	105

Table 20. The importance of community support

Other results of the community support question included:

- 92% carers and 81% non-carers rated community support as 'very important' or 'important'.
- There was no discernible-age related pattern.

The survey also asked about the importance of talking to others in similar circumstances:

I am able to talk to other people who are experiencing similar challenges to me to help me to feel better

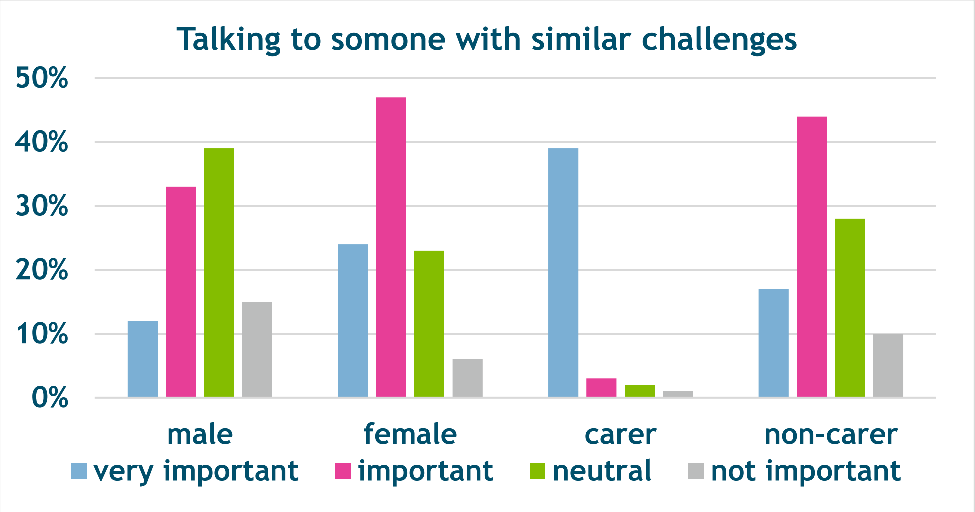

Chart 7. The importance of talking to someone with similar challenges

Put another way, the results show that 47 (71%) females, 15 (45%) males, 9 (69%) carers and 54 (61%) non-carers rated talking to others facing similar challenges as either 'very important' or 'important'. So, more females and carers feel talking to someone else in similar circumstances makes them feel better.

The dementia interviews provided rich details of the experiences of community support as follows:

"We got on with living [after his diagnosis] - we're involved with the church… the lady who lives down the road is further on the dementia pathway and she gave us the leaflet about the memory cafe and the castle events. Jim was reluctant to go but it was the best thing because it put us in touch with social services. We now have a social worker and the Admiral nurses. I now have some help with a cleaner in the house. It sometimes got on top of me. We're hoping Rutland Community Ventures will carry on with their courses but we know it's down to funding… It's nice that people are talking about it [dementia] these days. A neighbour had it about 8 years ago and they didn't talk about it. Men are more reluctant to talk about these things. The neighbour became quite aggressive and was sectioned. We didn't realise what her husband was going through. The Admiral nurses are good."

"I've had excellent support. Our GP referred me to the Admiral nurses and they've been good. Social services have helped me, too. They have organised for me to have a break… I think Jane's retirement triggered the dementia. She felt she wasn't needed any more. She didn't see people so much."

"There is a real risk of social isolation where we live and we want to keep her involved for as long as possible. There are different systems which can be confusing - Admiral nurse, Age Concern, Social Services. It can be overwhelming, dispiriting, expensive. We feel a bit as if we are in a limbo. There should be some way of alerting people to the statutory services for pensions and benefits and things like Age Concern and this Cognitive Stimulation Therapy pilot here in Oakham. We've got the council tax relief now for Mum."

The report from the focus groups with people with learning disabilities and additional needs suggests there is a need for better communication about social activities:

"Most young people wanted a lot more communication about services available to them, but they want it in a way they could understand. They also wanted more people to tell them about activities they could take part in. These people, they said, should be people they know."

The free text section in the general survey included the following comments relevant to community activities:

If there was one more thing that would help you live a healthy life, what would it be?

"More social interaction for those who live alone to relieve loneliness and the associated anxieties."

"More exercise classes available at night at affordable prices, no gym membership tie in."

"Access to free local services to maintain and or improve both my physical and mental health and wellbeing.

"Now approaching 80, I would welcome the opportunity to attend 'keep fit' sessions such as Sitting Tai Chi without having to be referred by my GP, thereby taking responsibility for my own wellbeing."

"Encouragement to walk more. PE lessons for people that aren't active and physical."

The Long Term Plan has mandated the introduction of 'social prescribing' to overcome social isolation and revive 'community'. The results shown above indicate that more opportunities (and better signposting to them) for exercise and social interaction will be welcomed by the Rutland population.

However, care in the community often means that family members and friends might also be involved in delivering care in the home. The data was further analysed to better understand how the respondents in the general survey might feel about this. The results are shown in the following table 21:

	I want my family and me to feel supported at the end of life	**I want to stay at home as long as it is safe to do so**	**I want my friends and family to have the knowledge to help and support me**
Very important	86 (82%)	81 (77%)	68 (65%)
Important	14 (13%)	17 (16%)	27 (26%)
Neutral	3 (3%)	5 (5%)	8 (8%)
Not important	2 (2%)	1 (1%)	2 (2%)
No reply		1 (1%)	
Total	**105**	**105**	**105**

Table 21. The importance of home, family and friends

The results show that staying at home is 'very important' for the majority (77%). To facilitate this, the respondents also rate support for their family members as 'very important' (82%). Fewer respondents (65%) rated their friends and family having knowledge to help and support as 'very important', however. This sends a clear signal that proposals in the Long Term Plan to keep people at home and out of acute hospitals will be appreciated in Rutland.

The next and final results section explores what Rutland people think about continuity of care with the professionals they encounter.

Section summary

- Women seem to be more engaged than men in health and care matters.
- Women seem to value community support more than men.
- People want to stay in their own homes as long as possible.
- Younger people want their time to be valued more than older people.
- Community support is not rated as quite so important as other features proposed in the survey but people express a wish for community facilities and activities in the survey free text options and dementia patients' interviews.
- Young people and young adults with learning disabilities and additional needs need better signposting to community groups and facilities for them.
- Those living with dementia value community support and activities highly but also want better signposting to activities, social groups and social benefits.

Continuity of care

Continuity of care is often subdivided into: ‘*informational continuity*’ of the patients’ medical history and social circumstances which facilitates appropriate treatment; ‘*management continuity*’ which refers to consistency in the medical management of an illness; and ‘*relational continuity*’ which describes an ongoing and consistent relationship with a medical professional (Heggarty, et al 2003).

Informational continuity featured in this report section, ‘*The NHS and Information and Communications Technology*’. Here, survey respondents across Leicester, Leicestershire and Rutland all demonstrated that being able to manage their own records for continuity in care was important but not so emphatically as other features of care such as access to care when needed or convenient travel. Also, Rutland people demonstrated a slight trend towards a lower rating of the importance than their Leicester and Leicestershire counterparts. Lack of informational continuity in this report section, ‘*The Interface Between GP and Acute Hospitals*’, was a cause of much dissatisfaction. It is not within the remit of this report to discuss the medical management of patients’ illnesses. However, relational continuity was an emergent theme in the free text options in both surveys, the focus groups and the semi-structured interviews.

The long-term conditions survey asks respondents to determine, at different stages of their illness, whether they wish to wait longer to see a professional they already know or have an earlier appointment with an unfamiliar professional sooner as follows:

What is important to you…:

	When first seeking help	When you received your diagnosis and treatment and options explained	During initial treatment or support	During your long-term support
Seeing a health professional you normally see but you may have to wait	13 (27%)	22 (46%)	20 (42%)	28 (58%)
Seeing any medically appropriate professional who is free immediately	19 (40%)	15 (31%)	15 (31%)	9 (19%)
Don’t mind	11 (23%)	6 (12.5%)	6 (12.5%)	6 (12.5%)
No reply	5 (10%)	5 (10%)	7 (15%)	5 (10%)

Table 22. The importance of continuity in care as a long term condition progresses

Table 22 shows a trend in increasing numbers of people who are prepared to wait to see a professional they know as their illness progresses. The deviation from this trend is during the initial treatment or support and after first seeking help and receiving a diagnosis. Conversely, people are more prepared to have a speedy appointment with any suitably qualified person when they first seek help. Patients with long-term conditions seem to build up important effective and emotional relationships with professionals which are, as stated earlier, built upon a partnership of trust, care and support.

Free text comments in both surveys also demonstrate that patients value relational continuity of care as shown below:

> *"Original consultant retired. Change did not prove satisfactory. This led to change of consultant to a hospital further away." (long-term conditions survey)*
>
> *"I was working with a mental health support worker (Turning Point). Have been waiting for a month for a new mental health worker. I have some difficulty with reading and writing. I have physical health problems, a heart condition and have mental health issues." (general survey)*
>
> *"Consistency with professionals. Complex needs including a learning disability require understanding the person to know how to treat them. This can only be achieved with consistency." (long-term conditions survey)*
>
> *"Doctors are overworked. I don't like seeing different doctors all the time. Not all understand me and my health issues." (general survey)*

The report of the focus groups with young people and young adults with learning disabilities, autism and/or additional needs states:

> *Continuity of key health professionals and service delivery itself right across the board. Different faces, different approaches, different places, and different language [are frequently experienced and cause extra anxiety.]*
>
> (Also see relevant extract of report on page 21)

The interviews with dementia patients and their carers posed two contrasting opinions. As shown in the following text box, Ella, demonstrates the value of seeing the same doctor when making a dementia diagnosis but John shows the problems of continuity although he does not explicitly mention the professional involved:

> *Ella: The doctor didn't think there was a significant problem and asked him to go back in three months. The same doctor did the same tests and noticed the deterioration and referred him to the memory clinic. He saw a memory nurse in Melton Mowbray within about 8 weeks.*
>
> *John: Memory Clinic is a waste of time. Been referred 3 times for memory issues and the same tests used each time so I remembered the answers!*

Evie, though, writing about her experiences before she died, also articulated the problems when relational continuity is destructive. Evie saw the same doctor many times but a satisfactory working relationship between patient and doctor was never achieved as she describes below:

> *When I first met her [the doctor] I did inform her that my past medical history was complex and that I could be difficult to treat, having a special regard to all my many allergies. It would appear to me and my husband that because I did not fit the pattern of a 'normal' patient, I became too much of a problem and I was treated with disdain and with not one ounce of compassion [….] To add insult to injury, on my last appointment with her she glibly informed me that if I had been seeing her at [her other] Clinic 'I would have been discharged several weeks ago.' To be told in a round-about way, 'Go away. Think yourself lucky, I have seen you at all!'[sic]*

Evie and her husband became so unhappy with the care they were receiving that they asked to be transferred to another hospital trust and informational continuity became a problem.

Therefore, this section demonstrates the value of relational continuity for patients if there is a good working relationship. When the relationship is disrupted, not offered or unsuccessful, patients can become very upset. John's words about the repeated dementia diagnostic tests suggest there should be varied formats for accurate diagnosis.

Section summary

- This section presents the concept of 'relational continuity'.
- The long-term conditions survey results demonstrate that patients build relationships with health and care professionals as their illnesses progress to the extent that they become more prepared to wait to see a known professional.
- A good professional-patient relational continuity is highly valued by patients.
- Disruption or absence of relational continuity can cause distress – especially for those with mental health problems or learning disabilities and autism.
- Relationships can fail and continuity of care in a failing relationship is destructive rather than constructive.
- Variations in the standard dementia diagnostic tests should be considered and relational continuity is important in confirming cognitive decline.

Conclusion

This was a wide-ranging public engagement exercise aimed at understanding what Rutland people have experienced when dealing with health and care services, what is most important to them and what their hopes for and expectations of health and care services are for the future. As each section of the results has already been summarised, this concluding section will be utilised to reflect more on the results.

As Rutland is one of the least deprived areas in England, affluence might be reflected in the greater percentage of respondents than in Leicester or Leicestershire, who depend on private car ownership (their own cars or those of others) for accessing health and care services. But we also suggest that there is a self-perpetuating cycle occurring in Rutland where people own cars because public transport is so limited. Public transport therefore attracts fewer customers and become uneconomical, so bus and train timetables are limited further. People, especially the ill and disabled, find public transport too difficult and intermittent for easy access to health services, so they depend on private cars. There is, we suggest, a risk that those who are the least affluent and/or unable to drive might be disadvantaged in their access to health and care services if public transport is not improved or care closer to home and greater use of local facilities are not introduced.

In common with the rest of the country, access to health and care services is shown to be further compromised by pressures on Rutland GP services and the consequent difficulties in getting an appointment to see a doctor. Relational continuity of care suffers as people are having to see any available doctor. The long-term conditions results, survey free text comments clearly show that people prefer to see somebody they know for continuing health problems. It is to be hoped that the introduction of a wider multi-disciplinary team into general practices might relieve some of the pressure on GP appointments and facilitate greater continuity of care.

However, the results also demonstrate a lack of informational continuity at the interface of primary and secondary care. Here, people at their most vulnerable are experiencing a worrying sense of being ‘lost’ in a complex web of communications over which they feel they have little control. Yet, when asked in the general survey to rate the perceived importance of self-managing personal records to improve relational continuity, Rutland respondents, like their Leicester and Leicestershire counterparts did not think this as important as other features such as convenient travel or access to health and care services when needed.

This slow access to services is shown to be a bigger problem for those with mental health conditions, although Government targets seem to have successfully speeded up access to specialist care for those with cancer. This discrepancy between mental health and cancer patients in satisfaction with care is perpetuated across the whole Leicester, Leicestershire and Rutland Better Care Together area.

Furthermore, once an illness has been diagnosed and treated, the stated aim in the Long Term Plan is to support people to stay at home for longer, self-manage their own conditions and avoid, as much as possible, emergency admissions to hospital. This seems to be a popular policy for the Rutland public. Healthwatch Rutland has, though, concerns. This ‘home first’ policy depends on three crucial elements being in place for safe and effective care being delivered: 1. A sufficiently qualified, experienced, fully staffed and flexible workforce able to offer care and support as soon as it is needed; 2. Improvements in communications to avoid gaps in care delivery; and 3. Patients’ significant others being prepared and able to supplement the care given by professionals.

People thus recruited into the role of ‘carer’ (the results indicate this is mostly females in Rutland) also have their own needs for support and access to health and care services. As the statistics and dementia interviews have shown, many carers are elderly and approaching a time when they, too, will be experiencing their own health problems.

The dementia interviews and learning disability focus groups also raised concerns about digital exclusion. Those with impaired cognition are least likely to be able to access information and communication technologies to facilitate better interactions with the health and care services. Whilst the policy direction is towards ever greater use of ICT, commissioners and providers of care need to be mindful of the disadvantages and inequity likely to arise for those who find themselves digitally excluded.

Finally, although the survey results demonstrate lower ratings for the value of community support and facilities, the free text comments showed a much greater enthusiasm for them. However, in this there are striking gender differences in approaches. As one of the comments from a dementia carer says, ‘men are reluctant’ to get involved or to talk over their challenges with others. We suggest that this is acknowledged when local policies for social prescribing are advanced.

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About Healthwatch Rutland

Healthwatch Rutland is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as "Enter and View") health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Rutland and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

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About Connected Together CIC

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Rutland.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures

Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

Connected Together
First for Community Engagement

VOLUNTARY IMPACT NORTHAMPTONSHIRE

University of Northampton

Appendix 1 - Supplementary Rutland demographic details

Christian	No religion	Not stated	Muslim	Other	Buddhist	Hindu
68.2%	23.4%	7%	0.4%	0.4%	0.3%	0.2%

Table 23. Rutland Population by religion (2011 Census)

English	Other European	East Asian
98.2%	0.8%	0.3%

Table 24. population by main language (2011 census)

White British	**92**	**88%**
White other	4	4%
Asian British	1	1%
Black British	1	1%
Other mixed ethnicity	1	1%
Other	2	2%
Blank	4	4%
Total	105	

Table 25. General survey respondents by ethnicity

Heterosexual	**88**	**84%**
Prefer not to say	7	7%
Gay/lesbian	1	1%
Other	3	3%
Blank	6	6%
Total	105	

Table 26. General survey respondents by sexual orientation

Appendix 2 - Focus groups and semi-structured interview outline questions

The Focus Groups

The proposed structure of the Focus Groups for people with learning disabilities and/or additional needs and their carers:

The Learning Disabilities focus group script

1. “Hello, I’m Jacqui” (remind group who you are and how they know you).
2. Ask them if they know about their condition. Ask them what is it called?
3. Now we are going to ask you about where you have visited, with your mums, your dads or your carers…. When you have been into hospital…. Or visited the doctors…. Or maybe gone to the opticians to have your eyes tested. We will ask about these 1 at a time by showing you a picture (icons of hospitals, doctors as in easy read surveys) and then you can …

    a) Draw a smiley face on the picture with a marker pen.

    b) Add a sticky - on emoji.

    c) Or point to one of our printed emoji cards (taken to groups).

4. Follow up on 3. “oh, dear did you not like it there?” then asking the question – ‘Why’. Or “coming here makes you happy, look at that happy face 😊 Tell me why it makes you happy…”.
5. Technology. Now we have an action-man toy on the table (could be a teddy if works better). He has a special band on his body that can show when he is not feeling well. Would you want to wear a band to show us when you are not feeling well? (Jacqui show arm with band on.)

    a) If yes, where?

    b) If no, why not? (record exact verbal answer)

6. Who likes going to basketball?   What other sporty stuff would you like to do? If

    they say they just don’t like sport, ask them about other ‘active’ activities that are not sport such as day trips out, walks and things like model-making club, art clubs etc Ask them what kind of club they would like to have set up the most? It might be gardening! Gardening is still moderate exercise.

7. Thank the group and then ask them if they have any more questions. Take 3-5 mins of questions.

The Dementia semi structured interviews

The suggested open-ended questions for the semi-structured interviews with patients with dementia and their carers:

1. Can you tell me a bit about getting your diagnosis?
2. What social activities do you like or would you like to try?
3. How do any travel issues affect what you can do or where you can go?
4. What technology (things like computers or monitoring) do you use? How does it help?
5. What have you found in your experiences of dementia to be really helpful?
6. What criticisms, if any, do you have of the help provided by health and social care services and what could be made better?
7. For the carer – how do you rate your own health?
8. What plans, if any, have you made for the future?

Appendix 3 - The report on Evie's and Tiny's story

Introduction

Evie was 64 in 2015 when she discovered a malignant breast lump and her husband, Tiny, was 79. For all Rutland patients, secondary care is provided by hospital trusts in either Grantham, Peterborough, Kettering or Leicester. From 2015 to 2018, Tiny and Evie struggled to navigate NHS health and social care systems at a time when plans were developing for greater service integration. Their story draws out five themes within the NHS Long Term Plan (2019).

1. Communication and personalised care

Poor communication often resulted in poor personalised care. Evie could not get diagnostic detail from nurses and her registrar spoke too fast and used complex medical terminology. On admission for a procedure, they waited while nurses chatted. When eventually acknowledged, they were informed they were not expected. One hospital department did not know whether another had arranged an echocardiogram. Tiny remains frustrated about poor communication between different hospital Trusts. When Evie attempted suicide as a mental health unit inpatient, the staff failed to notify Tiny for 8 hours. Evie's words below sum up her whole experience of lack of personalised care:

> *"It would appear to me and my husband that because I did not fit the pattern of a 'normal' patient, I became too much of a problem and I was treated with disdain and not one ounce of compassion."*

2. Integrated care

The lack of communication between hospital and ambulance staff meant that Evie travelled by ambulance with another patient who was given the only bed. Evie had to sit for the whole journey, which included a long detour, suffering excruciating back pain. Evie later had to arrange for practice nurses to remove the sutures left in by hospital staff. On discharge there was no co-ordination with community services resulting in a 14 day delay before home care services were in place. A professional from Derbyshire failed to deal with a faulty syringe driver as her key did not fit Leicestershire equipment.

3. Staff recruitment and retention

Tiny makes the most telling comment about workforce issues:

> *"She [district nurse] indicated that she was so concerned about low levels of staffing and proper levels of care available to her patients, that she had … tendered her resignation.*

C. [MacMillan Nurse] visited Evie, but not for a couple of weeks after we had called (her busy workload had prevented an earlier visit).”

4. Carer Support

Evie died aged 67 and Tiny was 82. The only psychosocial support offered to Evie involved a daily 150 mile round trip for her which would have involved Tiny as her driver. Tiny might have had some relief from carer duties when Evie was admitted on several occasions to a hospice. These admissions were time-limited and Tiny would, presumably, have needed to absorb visiting times into his daily routines. The hospice at home service, though, provided the couple with support.

5. Medicine management.

Tiny’s entries tell of many difficulties in managing Evie’s medications as he became an unwitting custodian for drugs and responsible for their administration. This is of particular relevance as Tiny was caring for Evie when she was physically and emotionally frail and making attempts to end her life.

Recommendations

With the themes drawn from this case study, recommendations include:

a) Improved communications would make the patient and carer experience less stressful.

b) The case study supports the stated aims to move to Integrated Care Systems with the removal of bureaucracies and technological difficulties involved in working across traditional boundaries.

c) Staff recruitment and retention is a national problem caused by multiple factors. Hopefully the measures proposed in the Long Term Plan to address these problems, will be carried through and prove successful.

d) Carers are now acknowledged as vital to the successful provision of health and social care services and it seems likely that more people will find themselves becoming carers in the future. Measures to support carers more will be welcomed.

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