

Leaving Hospital

Patient-Centered Discharge

2018



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Acknowledgements

Healthwatch Stoke-on-Trent would like to thank the staff at University Hospitals of North Midlands, City of Stoke-on-Trent Council Social Work staff and survey respondents for their help in completing this report.



Healthwatch Stoke-on-Trent is a local consumer champion, empowered with statutory powers to strengthen the voices of health and social care services.

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Executive Summary

The local health and care economy is changing. The Sustainability and Transformation Partnership (STP)¹ and initiatives like My Care My Way² are likely to change the way in which people experience health and care services. Healthwatch Stoke-on-Trent has been listening to understand what people think about these changes as they are introduced. For example, many people shared views about proposed changes to the way community hospitals would be used in the future, these were pulled into a report that was shared with the local Clinical Commissioning Groups (CCGs)³.

This report is about hospital discharge and builds upon a previous study carried out in 2015⁴. The older study found that there were improvements to be made in the way that patients and staff communicate. Since then, things have changed. There have been changes to the way that people are discharged from hospital. Also, there has been innovative work going on to encourage patients to participate⁵ in their care. This report finds that many patients do want to be involved.

The findings enclosed suggest positive changes in communication and that it has improved at UHNM. Also, the data collected from those who responded to the survey suggests that people feel slightly more prepared for discharge than they did in 2015 despite well publicised pressures in the health and care system. The findings indicate a possible link between communication on the ward and how resilient patients are once home, further reinforcing its importance. There is room for improvement though. There are differences in patient experience when comparing different discharge routes (see page 46). For example, those receiving rehabilitation in the home reported feeling least able to manage their condition.

This report makes some recommendations that may help to maximise patient involvement and subsequently, patient outcomes.

¹ <http://www.twbstaffsandstoke.org.uk/index.php>

² More detail here - <https://www.northstaffsccg.nhs.uk/stoke-get-involved/consultation-engagement/my-care-my-way/my-care-my-way-the-model>

³ <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/HW-Stoke-Community-Hospital-Beds-FINAL.pdf>

⁴ <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/MCMW-Feedback-Report-Sept-15Final.pdf>

⁵ <http://www.uhnm.nhs.uk/news/pages/UHNM-patients-know-it-is-OK-to-ASK.aspx>

Recommendations

- *Communications surveys should be designed to incorporate resilience. This would help to 'join up' the pathways and understand their effectiveness.*
- *To further study of patient pathway number three (rehabilitation at home) to better understand patient experience and opportunities for improvement.*
- *To understand the extent of patient participation projects such as It's ok to ask'. Do they continue through the patient pathway? For example, through to home?*
- *Healthwatch Stoke-on-Trent and partners can work with staff to identify where on pathways communication can be improved.*
- *Ensure that patient experience is measured alongside any drive for efficiency.*
- *Current strategies that may improve patient participation should be built upon.*
- *Volunteers to support patient participation.*
- *Healthwatch Stoke-on-Trent to develop a question prompting sheet and facilitate with patients (using volunteers).*

Introduction

Healthwatch exists to enable a strong voice and provide support to local people and community to influence the way their health and social care services are planned, purchased and provided. This report does this by sharing the experiences of those that use services with those that provide them. It is hoped that these views can be used to improve patient experience and outcomes in the future.

This report looks at:

- The patient experience of hospital discharge;
- How the patient experience of hospital discharge has changed because of service changes;
- How communication may affect patient outcomes;
- If there is any identifiable difference in patient experience on different pathways.

My Care My Way, Home First⁶ (MCMW) is a significant service change, it is a new model of care. In other words, a new way of caring for the patients of University Hospitals of North Midlands NHS Trust (UHNM). A key element of MCMW is its emphasis upon moving care closer to home. This means a change to the way in which patients can expect to be discharged from hospital. For example, they are more likely to receive any further care they need at home rather than in a community hospital (the areas covered in this report can be found on page 46). The hope is that this will lead to better patient outcomes because it helps to address the risks associated with prolonged bed stays, such as muscle deterioration⁷.

There has been work done to assess initiatives such as MCMW, albeit not particularly focussing on patient experience. For example, Monitor (an organisation that helps NHS organisations to improve) developed a literature review of clinical impacts⁸. Recently, the

⁶ More detail here - <https://www.northstaffsccg.nhs.uk/stoke-get-involved/consultation-engagement/my-care-my-way/my-care-my-way-the-model>

⁷ <https://www.stokeccg.nhs.uk/generic-publications/my-care-my-way/342-annex-a-case-for-change-mcmw-october-2015/file>

⁸ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/459268/Moving_healthcare_closer_to_home_clinical_review.pdf

What happens next?

The Home First programme is centred on supporting our patients to return home as quickly as possible following assessment and treatment. This means that involving and supporting patients to return home, with the correct support, will always be our first priority.

With your full involvement you will either be:

- Discharged home to continue to live independently or with any family/carer support that you may have had prior to your hospital admission.
- Discharged home with extra support if this has been identified and agreed following assessment.
- Transferred to a rehabilitation hospital if you need further therapy before going home.
- Transferred to a care home setting i.e. residential or nursing home to complete further assessments before being discharged home.
- Discharged to a permanent care home setting i.e. residential or nursing home.



NSH 8119

Discharge leaflet from UHNM 2016

West Midlands Clinical Senate broadly supported the implementation of the model in terms of clinical merit and patient care (with recommendations for improvement)⁹.

In understanding service change, Healthwatch Stoke-on-Trent sees the design of human experiences (such as how a person experiences being in hospital) as distinct from the design of processes¹⁰ (that are in place to manage the time in hospital). For example, a process that improves patient flow (such as Red to Green- see weblink¹¹) can be measured in its effectiveness but this may not adequately describe patient experience. Although clinical outcomes, care and effective systems are of critical importance, this paper attempts to map out the patient journey in terms of experience.

In 2015 Healthwatch conducted a study¹² focussed upon the elderly intended to influence the design of MCMW by contributing towards early engagement and consultation. Carried out before the new model was rolled out, it was found that

some patient and staff communication was not as effective as it could be. For example, a significant number did not know what was happening to them whilst in hospital. Others said they didn't receive information about medication before discharge. If successful, periods in hospital will be shorter under MCMW (and other improvements to patient flow in

9

http://www.wmscnsenate.nhs.uk/files/4415/0296/7921/North_Staffordshire_and_Stoke_on_Trent_CCG_-_response_to_CCGs_v5_FINAL.pdf

¹⁰ Bate and Robert, 2006, Qual Saf Healthcare 15(5) 207-310

¹¹ <http://www.uhnm.nhs.uk/Pages/Red2Green-Workshop-success.aspx>

¹² <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/MCMW-Feedback-Report-Sept-15Final.pdf>

the hospital such as Red2Green¹³) meaning that patient journeys will be different from those when the last study was carried out. This suggests the need for this report as it monitors how patient experience has changed in response.

The 2015 report identified the importance of communication between staff and patient because it enables patient participation in their care. In a 2017 Healthwatch England report,

“My dad was just a number” -
Respondent 98 (Pathway 1)

“What happens when people leave hospital and other care settings”, the number one issue was that people didn’t feel involved in decisions¹⁴. Healthwatch Dudley focussed upon communication at discharge in the report, *Patient Experience of Hospital Journeys*¹⁵. Increased patient participation has the potential to help people feel confident to manage their condition¹⁶. Not only this, but keeping things patient centred in this way is something that features heavily in the Five Year Forward View¹⁷. Without effective interaction between patients and staff it is difficult to see how care can be patient-centred¹⁸.



(left) The Patient-centred approaches framework is an example of best practice¹⁹

As well as MCMW, the patient experience is now different in other ways at the hospital. For example, there is now a program called ‘It’s OK to ask!’²⁰ that encourages patients to ask questions about their care. This health literacy²¹ based project aims to improve levels of patient participation by giving patients the tools to interact with staff. In theory, this intervention and others

¹³ <http://www.uhnm.nhs.uk/Pages/Red2Green-Workshop-success.aspx>

¹⁴ <http://www.healthwatch.co.uk/news/people-share-their-experiences-leaving-hospital>

¹⁵ <http://healthwatchdudley.co.uk/wp-content/uploads/2016/02/Patient-Journey-Report-Final.pdf>

¹⁶ <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/MCMW-Feedback-Report-Sept-15Final.pdf>

¹⁷ <https://www.england.nhs.uk/ourwork/patient-participation/>

¹⁸ More info here - <https://www.england.nhs.uk/integrated-care-pioneers/resources/patient-care/>

¹⁹ <http://www.skillsforhealth.org.uk/news/latest-news/item/576-new-framework-to-promote-person-centred-approaches-in-healthcare>

²⁰ See <https://player.vimeo.com/video/203449713>

²¹ <http://webapps.stoke.gov.uk/uploadedfiles/Health-Literacy-short-strategy.pdf>

(such as ‘Hello, my name is²²’) can be understood as enabling the patient, carer and staff participation needed to learn the skills required to cope once home²³. This paper briefly explores this and how it might affect resilience (see leaflet on page 22).

This paper also compares the different ways in which patients can be discharged. For example, being discharged with domiciliary (care workers for example) and primary care (the GP for example) compared with intermediate care (rehabilitation for example) in the home. It compares the new data with the results of the previous study to see how different elements of patient experience have changed.

The findings of this report suggest that the focus upon communication with programmes such as ‘It’s OK to ask’ may be having an impact. On the measures related to this area in the survey, the trends are positive, some more than others. For example, the number of respondents who said they didn’t find it easy to talk to staff fell when comparing the 2015 and 2017 cohorts. This continues through to

“Pathway B - Discharge from hospital was very rushed.”
” - Respondent 132 (Pathway 2)

discharge where fewer respondents said they weren’t asked about what help they needed at home. Importantly, the data in this report indicates a possible correlation between those who talked to staff or were encouraged to ask questions and how confident they were to cope with their condition once home. This would further validate the work ongoing around communication at the hospital. The findings show that after recent changes such as MCMW and quicker patient flow, this cohort report feeling more prepared for discharge overall now than in 2015. However, there is some variation across the different pathways, with those destined for high impact rehabilitation in the home indicating being less so²⁴. Indeed, some comments received indicate a sense that discharge may sometimes feel rushed.

Whilst many of the findings are positive, there is still room for improvement. This report proposes a few recommendations that may help to work towards this. For example, there are regular NHS surveys, such as one about communication. An idea could be to extend this so that it examines the relationship between communication and outcomes, such as resilience. For patient experience, this would reflect the effectiveness of the whole pathway rather than just part. Also, work could be done to better understand why some

²² <https://hellomynameis.org.uk/>

²³ More about this - <http://journals.sagepub.com/doi/abs/10.1177/1460458212445500>

²⁴ LOW NUMBERS - Pathway A Domiciliary Care - 63 (46.7%) B Intermediate Care - 48 (35.6%) C - High Impact Rehab 24 (17.8%).

patients report being encouraged to ask and questions others not. For example, to what extent does having the support of friends and family affect staff engagement.

"I received a total hip replacement operation sept 2016. I am a widower. It was decided that living alone, I required an intermediate care plan. They took an extra 3 days to organise beyond my 'normal' 3 day discharge date. That extra 3 days made ALL THE DIFFERENCE to my full recovery. Patients are discharged too soon. Care team excellent but clearly under pressure"

" - Respondent 26 (Pathway 2)

There are obvious pressures on the health and care system²⁵ that are being addressed through improving patient flow. This paper recommends that there should be ongoing monitoring of patient experience alongside these changes.

The report also recommends that information provision be improved for patients on the wards as they progress towards discharge. Building upon initiatives such as 'It's OK to ask', this could take the form of a prompt sheet containing key questions for the patient to ask about their

treatment, discharge and social care. It could also have a social prescribing element that would help with more holistic support once discharged and improve links to programmes such as the Royal Voluntary Service's Supporting Your Recovery²⁶ or other befriending services. Volunteers could facilitate the use of the sheet and encourage participation. There is also the opportunity to better understand the reach of programmes orientated around patient participation to see if they extend to the home of patients. For example, does 'Its Ok to Ask' extend into the home? This could be focussed in areas that suggest lower levels of patient resilience in this report, such as pathway 3a (rehabilitation at home) (see page 46).

As more change is expected in the local health and care system in the future through for example, the Sustainable Transformation Partnership (STP); Healthwatch Stoke-on-Trent feels that recommendations in this paper would help to join up pathways in terms of experience. Healthwatch Stoke-on-Trent would like to thank all that have contributed to this report, be it respondents, partner organisations or staff. The intention is to work together in further improvement of outcomes for patients, their carers and families.

²⁵ <https://www.bma.org.uk/news/2017/january/hospitals-and-social-care-face-budget-cuts-of-twenty-six-billion-pounds>

²⁶ <https://www.royalvoluntaryservice.org.uk/volunteer/volunteer-opportunity/6232-volunteer-staffordshire?ServiceId=1205>

What We Did

Which discharge pathway was used?
(see page 46)

Was admission planned or unplanned?

Who is the respondent? (Carer or Patient).

Where does the patient live?

Does the respondent like to be involved in care?

How old is the patient?

Does the respondent have experience of hospital?

How ill was the patient?



Did the respondent have friends or family to ask questions?

Was the respondent encouraged to ask questions?

Did the respondent find staff approachable?

Did the respondent understand well what was going to happen to them?

Was the respondent asked how would like to be supported at home?

Was the respondent given clear medication instructions?

Did the respondent feel ready to leave at the time of discharge?

A questionnaire was devised in consultation with hospital (UHNM) and social care staff (see page 47). It also repeats elements of the 2015 survey²⁷. A patient cohort was identified by the hospital of over 75's discharged between June 2016 and April 2017 along one of three pathways: domiciliary care in the home (1), intermediate care in the home (2) and rehabilitation in the home (3a) (Pathway 3, bed based care, is outside the scope of this project. See page 46 for more detail). 500 surveys were distributed along each of these three pathways directly to the patients once they had been discharged, retrospectively.

135 responses were received (9% response rate). 77 of these contained additional comments. These comments were classified by theme. Quantitative (numerical) data was analysed using the software IBM SPSS and Microsoft Office applications.

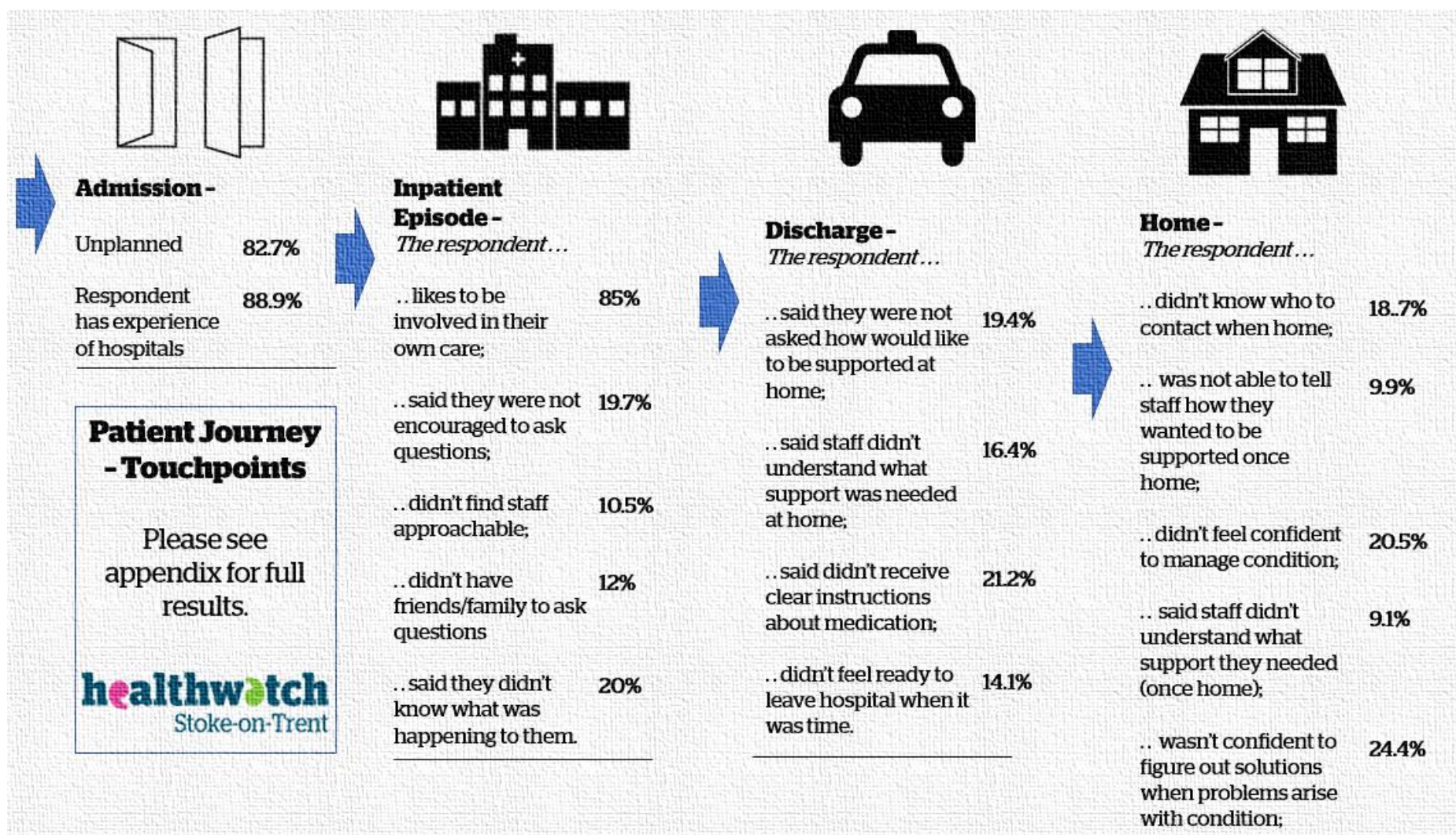
Did the respondent know who to contact when discharged?

Did the respondent feel able to manage condition once home?

Did the respondent feel confident to figure out solutions when new problems or situations arose with their condition?

²⁷ <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/MCMW-Feedback-Report-Sept-15Final.pdf>

Results on a Page



Further analysis and detail throughout the report.

Key Findings

Patient Experience of Discharge (all pathways)

- 19.4% reported that they were not asked how they would like to be supported at home.
- 16.4% said staff didn't understand what support was needed at home (in hospital).
- Once home, nearly **one in ten** said they were not able to tell staff how they would like to be supported.
- 9.1% said staff didn't understand what support was needed once home.
- Once home a fifth (20.5%) of respondents said they didn't feel confident to manage their condition. Nearly a quarter (24.4%) said they didn't feel confident to figure out solutions when problems arise with their condition.
- The six comments received about discharge comment upon the pace of it (see page 45).

How the Experience has Changed Between 2015 and 2017

- According to a comparison of this and the previous 2015 data, communication between staff and patient has improved at the UHNM:
 - Less respondents reported not receiving instructions about their medication (**26.9% 2015/19.8% 2017**);
 - Fewer respondents (**29.3% 2015/10.5% 2017**) reported difficulty talking to staff about their care;
 - There is an improvement in the numbers of those who reported not being asked questions about their care). (**26.9% 2015/19.8% 2017**);
- The proportion of those who described knowing what was happening to them whilst in hospital remained stable (**20% 2015/21% 2017**).
- Overall more of the 2017 cohort described feeling ready to be discharged when the time came than those in 2015 (**74% 2015/77% 2017**).

How communication along patient pathways may affect patient outcomes

- **89.6%** of patients (when they filled the survey as opposed to friends and carers) reported liking to be involved in their care.
- Nearly **20%** said they were not encouraged to ask questions.
- The data indicates a possible correlation between patient participation and levels of resilience. The levels of confidence in managing a condition varies upon how much the respondent was encouraged to participate (see page 22 onwards)²⁸.
- The data suggests that those who were encouraged to ask questions about their care were more confident to figure out solutions once home. **68.8%** of those that agreed they were confident doing this had been encouraged to ask questions. This falls to **19.4%** when they had not been encouraged to participate.
- The data suggests that those who weren't encouraged to ask questions were more than twice as likely to disagree they were able to manage their condition (**11.9%** compared with **28%** disagree).
- The data indicates that those who were encouraged to ask questions felt less ready to be discharged (**28%** felt ready when not encouraged, **7.5%** felt ready when encouraged).

²⁸ This is even more pronounced when carer responses are filtered out (see page 22)

The difference experiences of pathways

See **page 46** for description of pathways

The low number of surveys returned to Healthwatch Stoke-on-Trent means that once divided over three pathways means that this analysis should be treated with caution²⁹:

- Respondents due to receive rehabilitation at home (pathway 3a) reported feeling least able to manage their condition once home (**30.4%**);
- Respondents due to receive rehabilitation at home (pathway 3a) reported feeling least ready for discharge (**34.8%**).
- Respondents receiving high impact rehabilitation at home (pathway 3a) reported being less confident in the ability to manage the condition (**30.4%**);
- Nearly double (**17.4%**) the respondents receiving high impact rehabilitation at home (pathway 3a) disagreed that staff understood well what was happening when compared with the next pathway (domiciliary care **9.7%**).

²⁹ LOW NUMBERS - Pathway A Domiciliary Care - 63 (46.7%) B Intermediate Care - 48 (35.6%) C - High Impact Rehab 24 (17.8%).

Narrative 1 - The Patients and Their Experience

Amongst the comments received with questionnaires, there were 23 positive comments and 38 negative comments. Many of the positive comments mentioned the staff.

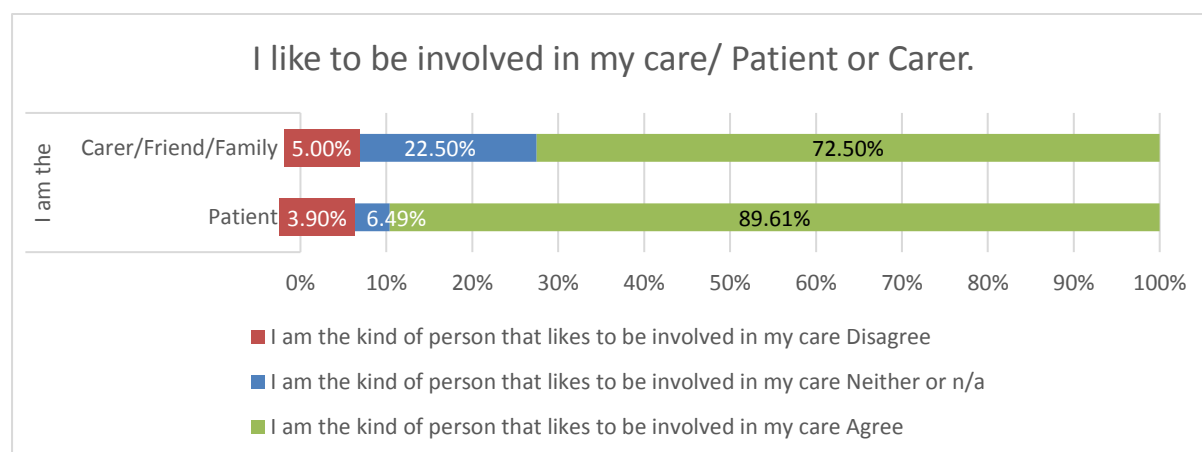
66% of these questionnaires were filled in by the patient themselves, the rest either by family or carers. These were distributed across the following pathways;

- 46.7% (n63) Acute Medical Episode Complete - Fit for transfer home for assessment of ongoing needs - Pathway 1;
- 35.6% (n48) Acute Medical Episode Complete - Fit for transfer home with intensive health support for assessment of ongoing needs - Pathway 2;
- 17.8% (n24) Acute Medical Complete - High Impact Rehabilitation(Home) - Pathway 3a.

The average age of respondent was 84 (within a range of 62-102) and spread across different localities (see page 42). It is safe to say that if social care or other services were delivered, it would have been so by a variety of different providers. Although the first part of postcodes was given by most respondents, this isn't enough to ascertain which local authority they belong to.

A considerable 88.9% of respondent had some experience of hospital in some way in the last five years giving them prior insight into the hospital environment. For 82.7% of respondents, their time in hospital was unplanned and perhaps unexpected.

85% of respondents agreed that they are the kind of people that like to be involved in the arrangement of their care. This is higher when filled by patients (table below).



20% reported not knowing what was happening to them whilst in hospital. 12% reported being without a friend or family member to ask questions on their behalf.

51.5% (19.9% not so) said that they were encouraged to ask questions about their care and 78.4% agreed that they found it easy to approach staff.

In preparation for discharge 19.4% said they weren't asked how they would like to be

"When discharged from hospital, nobody went through medicines with my dad, mum or myself, just put in a bag and given to us" - Respondent 120 (Pathway 3a)

supported at home (69.4% did).

21.2% of respondents said that they weren't given clear instructions about their medication before they left hospital.

"3 big operations, very well looked after and cared for pleasantly and well. Last time in hospital - very very upset and hurt when I wasn't ready to come home, wanted me out with no notice for family to arrange care. Very difficult time for us all, couldn't understand all the broken promises and change in attitude" - Respondent 129 (Pathway 3a)

76.9% agreed that staff in hospital understood well what support was needed at home (16.4% not so). On leaving hospital 76.8% said that they felt ready to do so (13.4% not so) and once home 77.6% said they knew who to contact about care plans or services (18.7% didn't).

71% agreed that they were able to tell people how they would like to be supported when they got home (29% not

so). 66.7% felt confident that they would be able to manage their condition once home (20.5% didn't).

"Hospital staff were outstanding as were social services team on my discharge" - Respondent 38 (Pathway 1)

Whilst at home, 79.5% said staff understood what support was needed (9.1% said they didn't). 58.7% said they were confident to figure out solutions when new situations or problems arise with their condition (24.4% said they weren't).

Narrative 2 – 2015/17 Comparison

The 2017 respondents have slightly more experience (89.9%) of being in hospital than the 2015 cohort (85.9%). Also, the 2017 patients were slightly more prepared for their time there (2015 unplanned 89.7% 2017 82.7%). This group reported having slightly less support from friends and family (9% in 2015 to 12% in 2017). Whilst in hospital 40% of this cohort described themselves as 6 or less out of ten when describing how ill they were. This is slightly higher than the 37.3% in 2015.

The number that reported they didn't know what was happening to them whilst in hospital fell from 21.3% to 20%. A big change is shown when participants were asked how easy it was to approach and talk to staff, with those saying they found it difficult falling from 29.3% (2015) to 10.45% (2017)³⁰. The numbers that said they didn't get clear instructions about medication on discharge fell from 28.8% to 21.2%. The number that said staff didn't speak to them or carer about how they would be supported at home fell from 26.9% to 19.8%³¹. At discharge they felt slightly readier to leave (73.8% in 2015 to 76.9% in 2017).

The recent cohort was more experienced or *literate* in being in hospital. This could suggest they are more likely to know how to *do* 'being in hospital'. They were also more prepared for their stay. However, less of them were unsupported by friends and family.

There has been much work ongoing at the UHNM also that may have impacted positively upon communication. For example, the work around 'Pyjama Paralysis'³² which aims to keep people active and out of bed to avoid deconditioning³³. This helps to address the risks associated with prolonged bed stays identified in *My Care My Way - Home First*³⁴.

³⁰ The text for this question was altered slightly

³¹ The text for this question was altered slightly

³² See - <http://www.bmj.com/content/357/bmj.j2096>

³³ <http://www.uhnm.nhs.uk/OurServices/Elderlycare/Pages/Deconditioning-Awareness-Campaign.aspx>

³⁴ <https://www.stokeccg.nhs.uk/generic-publications/my-care-my-way/342-annex-a-case-for-change-mcmw-october-2015/file>

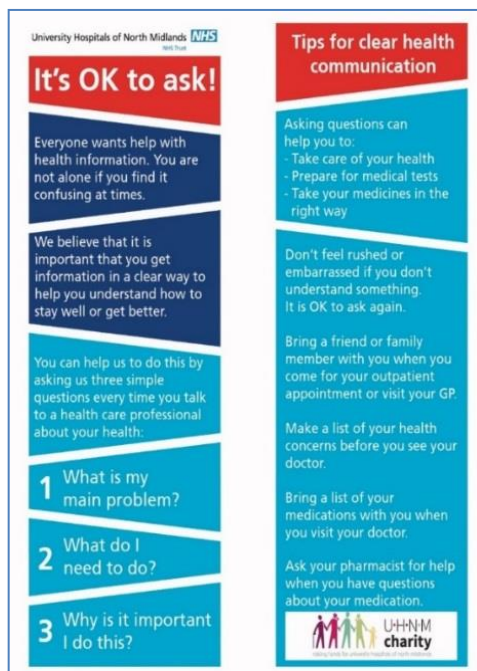
Comparing 2015 and 2017 - Diagram.

	 2015	 2017	
Respondents who have had experience of hospitals in the last 5 years.	85.90%	88.90%	
People who responded that said their time in hospital wasn't planned.	89.70%	82.70%	
Respondents that reported a 6 or less (out of 10 - very ill) when asked how ill they considered themselves to be while in hospital.	37.30%	40.5%	
Respondents that reported they didn't know what was happening to them whilst in hospital.	21.30%	20%	
Respondents reported that they did not find it easy to talk to doctors and nurses about their care/I found I did not find it easy to approach hospital staff*.	29.30%	10.45%	
Respondents that reported having a friend or member of the family who asked questions on their behalf.	71.00%	70.68%	
Respondents that reported having no support from friends or family.	9.00%	12%	
Respondents that said they didn't get clear instructions about their medication before they left hospital.	28.80%	21.22%	
Disagreed that staff spoke with them or their carer to discuss what would happen when they got home/staff didn't ask me how I would like to be supported at home*.	26.90%	19.84%	
Respondents that reported feeling ready to leave hospital when the time came.	73.80%	76.86%	

The 2015 Report - <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/MCMW-Feedback-Report-Sept-15Final.pdf>

*Question wording slightly changed.

Narrative 3 - Patient Empowerment



‘It’s OK to ask’ (left) is an intervention originally implemented at the University Hospitals of North Midlands. It is informed by Health Literacy³⁵ and the likelihood that some people may not engage in their own care, perhaps because they are embarrassed to ask or may put complete faith in medical staff, thus disengaging from their own care. This presents obvious risks if for example, there are delays in staff being able to attend once the patient is home. As suggested in the previous (2015) report³⁶, this group, the over 75’s may be less willing to question and therefore critically analyse what is happening to them. This will affect patient participation. ‘It’s OK to ask’³⁷ addresses

this by encouraging engagement between staff and patient. In effect, this intervention and others (such as ‘Hello, my name is’³⁸) are shaping the environment in the hospital by making staff aware of the issue and therefore empowering patients. It is enabling the participation needed to maximise outcomes once home. In other words, they would (theoretically) be more able to think critically about their care so they can understand and participate in it. Interactions with staff result in learning in less obvious ways, it certainly doesn’t have to be deliberate teaching. Therefore, initiatives such as ‘Hello, my name is’³⁹ are important.

“Lev Vygotsky (1962), a Russian teacher and psychologist, first stated that we learn through our interactions and communications with others. Vygotsky (1962) examined how our social environments influence the learning process. He suggested that learning takes place through the interactions students have with their peers, teachers, and other experts”⁴⁰

³⁵ An interesting discussion - <https://www.england.nhs.uk/blog/jonathan-berry/>

³⁶ <http://www.healthwatchstokeontrent.co.uk/wp-content/uploads/2015/06/MCMW-Feedback-Report-Sept-15Final.pdf>

³⁷ <http://www.uhnm.nhs.uk/news/pages/UHNM-patients-know-it-is-OK-to-ASK.aspx>

³⁸ <https://hellomynameis.org.uk/>

³⁹ <https://hellomynameis.org.uk/>

⁴⁰ <https://jan.ucc.nau.edu/lsn/educator/edtech/learningtheorieswebsite/vygotsky.htm>

In other words, as well as directly teaching (health literacy) skills, such as how to manage a condition, the environment in which learning takes place is constructed in a way that maximises the chances to learn.

Much can be learned about the hospital environment, those within it and how to make improvements. This sort of thinking applies to different health and care sectors and Healthwatch Stoke-on-Trent has been able to participate in the city-wide Health Literacy Steering Group. Health literacy is now a term understood in Stoke-on-Trent and has impacted sectors from charitable to pharmacy. The local Clinical Commissioning Group are in support of this work also. There is now evidence developed locally⁴¹ about health literacy, adding to the growing amount of information about communication practices nationally⁴². The findings in this report perhaps shine a further light upon the practical possibilities of communication based initiatives and potential outcomes.



What is Health Literacy?

Health literacy is 'the motivation and ability to access, understand and use information in ways which promote and maintain good health'.

Good health literacy has a very positive impact on people's health and wellbeing, as it enables people to understand their own and their family's health and health needs. Whereas poor health literacy has a strongly negative impact such as

- less healthy choices
- poorer health
- more hospitalisations and higher health care costs
- riskier behaviours
- poorer medicines adherence

As poor health literacy is more predominant in people from the most deprived backgrounds with the poorest health outcomes, then tackling this issue will have a positive impact on overall health outcomes for the city.

From Vision

Our ambition is that Stoke-on-Trent becomes a health-literate city in which:

- People understand their own health needs (and those of their families), healthcare services and how to use them appropriately
- Professionals understand and recognise the importance of good health literacy and adapt their practice accordingly
- Local organisations embed health literacy principles in their goals, policies and practice

In practical terms, this means that, by 2020, Stoke-on-Trent is a city which demonstrates the key attributes of a health literate city, and where we use the evidence to develop effective strategies to address the issues.

This will mean that health literacy approaches are embedded



To Implementation

We will work together with partners from education, early years, adult learning, local universities, primary care, hospitals, community and voluntary organisations to embed the health literacy agenda in everyone's area of work.

We shall ensure that partners feel supported as they learn about health literacy, and develop practices to embed it. We shall also aim to raise awareness of the issue and impacts of health literacy, engage in training sessions, and build up networks of partners and practitioners.

We shall provide opportunities for local people and professionals to learn about health literacy and to develop their own creative solutions to problems.

We shall enable people to come together to share their learning and their work, so that everyone can benefit from city-wide approaches.



Working together for the future

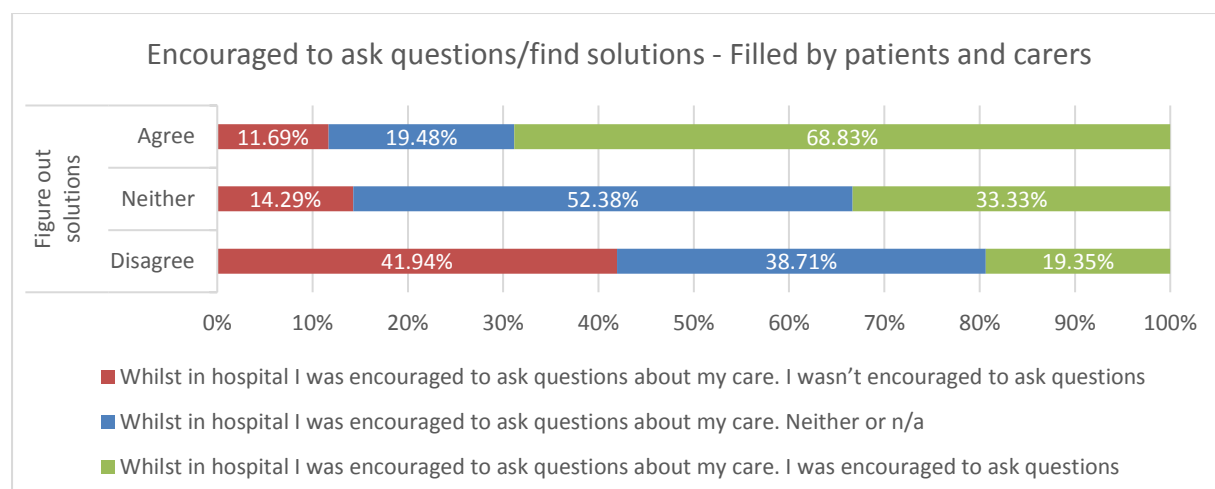
	self care	We will help people to make decisions for themselves relating to their management of long term health conditions.
	adult learning	Organisations which deliver adult learning will be encouraged to include health literacy in the courses that they offer.
	early years	Partners which work with young children will be helped to put health literacy into the things they do.
	digital inclusion	Partners across the city will ensure that as people's access to digital media and the internet improves, there will be a focus on health literacy.
	polices and procedures	We will aim to get health literacy considerations into decision making policies across the city.
	removal of barriers	We will work with partners including the NHS in particular, to make it easier for people to navigate healthcare systems and the wider health environment.

Source - <http://webapps.stoke.gov.uk/uploadedfiles/Health-Literacy-short-strategy.pdf>

⁴¹ <https://www.keele.ac.uk/pchs/implementingourresearch/makinganimpact/crosscuttingresearch/healthliteracy/>

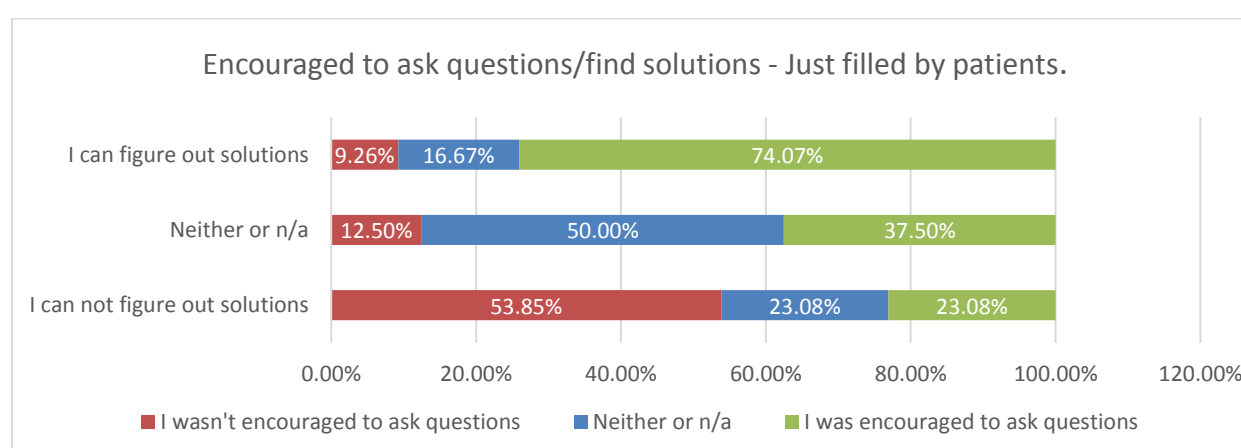
⁴² <https://www.pifonline.org.uk/wp-content/uploads/2017/05/PIF-PPI-Journey-4May17-final.pdf>

Does being encouraged to ask questions at hospital affect feeling confident to find solutions when new situations or problems arise with their condition once home?⁴³



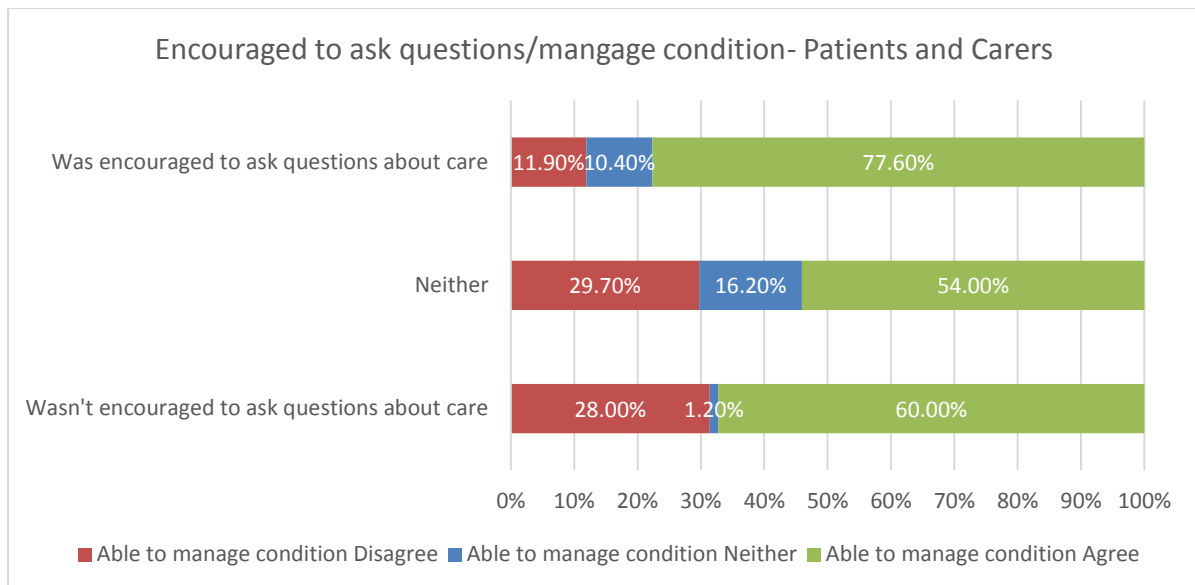
The findings suggest that those who were encouraged to ask questions about their care were more confident to figure out solutions when they arise with the condition. The above shows that 68.8% of those that agreed they were confident with doing this had been encouraged to ask questions. This falls to 19.4% when they weren't encouraged to participate.

When asking only the patients (below table) and removing those completed by carers 74% of those that they were confident to find solutions had been encouraged to ask questions. Of those that said they could not figure out solutions only 23% had been encouraged to ask questions.



⁴³ Encouraged n67 - Not Encouraged n25 - N/A n37

Does being encouraged to ask questions in hospital affect feeling able to a manage condition once home?

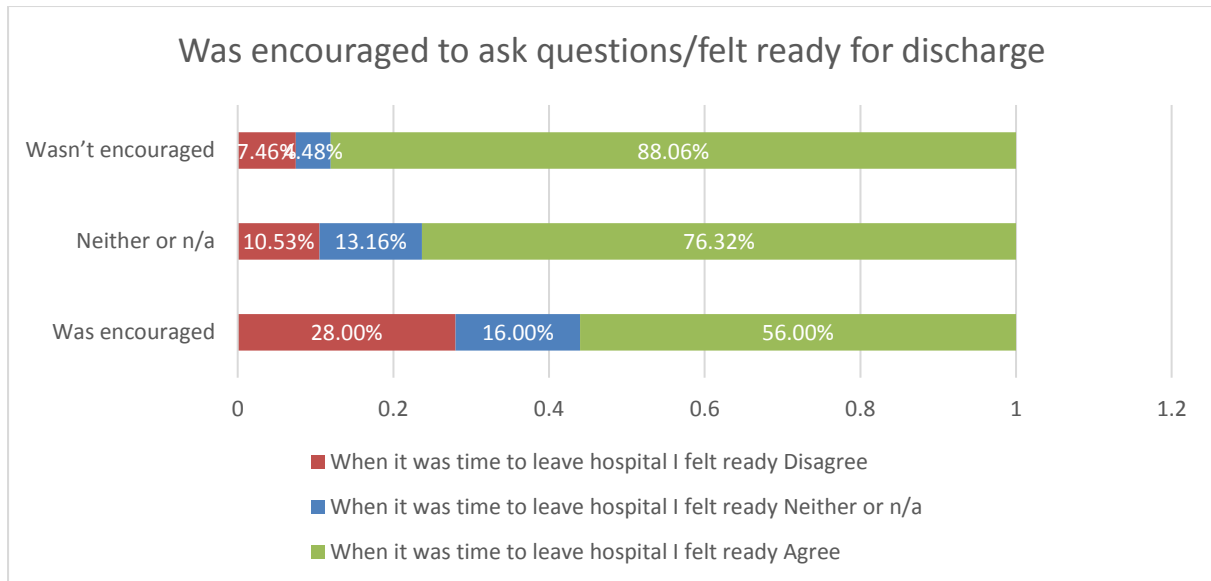


The above findings suggest that those who were encouraged to ask questions about their care are more likely to agree they feel able to manage their condition. Above, 77.6% of those who were encouraged to ask questions felt able to manage their condition. This falls to 60% for those who were not encouraged to ask questions about their care.

Those that weren't encouraged to ask questions were more than twice as likely to disagree they were able to manage their condition (11.9% disagree compared with 28% disagree).

"My dad doesn't acknowledge that he needs help. He believes that he is well and comfortable at home and able to care for himself. The family appreciate the fact that hospital staff fully included him in decisions made about dads welfare and safety" - Pathway 1

Does being encouraged to ask questions in hospital affect how ready for discharge one feels?⁴⁴



The data suggests that those who were encouraged to ask questions felt less ready for discharge when the time came (56%).



"The more senior hospital staff displayed in GENERAL, higher order communication skills such as questioning, clarifying esp the surgeons immediate team & wonderful critical care team" - Pathway 1

Communication at UHNM. Taken from the UHNM Red to Green twitter page - https://twitter.com/UHNM_Red2Green

⁴⁴ Encouraged n67 - Not Encouraged n25 - N/A n37

Narrative 4 - Pathways

The questionnaires were distributed along each of three patient pathways, 500 on each. The pathways are as follows:

- **Pathway 1 - Acute Medical Episode Complete - Fit to transfer home for assessment of on-going needs (Domiciliary Care).**

This pathway will be utilised when it is identified that the patient can be safely supported by primary care within their own home setting but need assessment for on-going support from domiciliary care services.

- **Pathway 2 - Acute Medical Episode Complete - Fit to transfer home with intensive health support for assessment of on-going needs (Intermediate Care)**

This pathway should be used for patients that can be safely supported by primary care (GP's) within their home setting but require further support from health and social care teams to reach and maintain an optimum level of recovery. The model will align to the intermediate care model as described within NSF Older People⁴⁵, which includes on-going assessment by the multi-disciplinary team to determine long term needs. This may include a care package, on-going District Nursing or Community Matron case management.

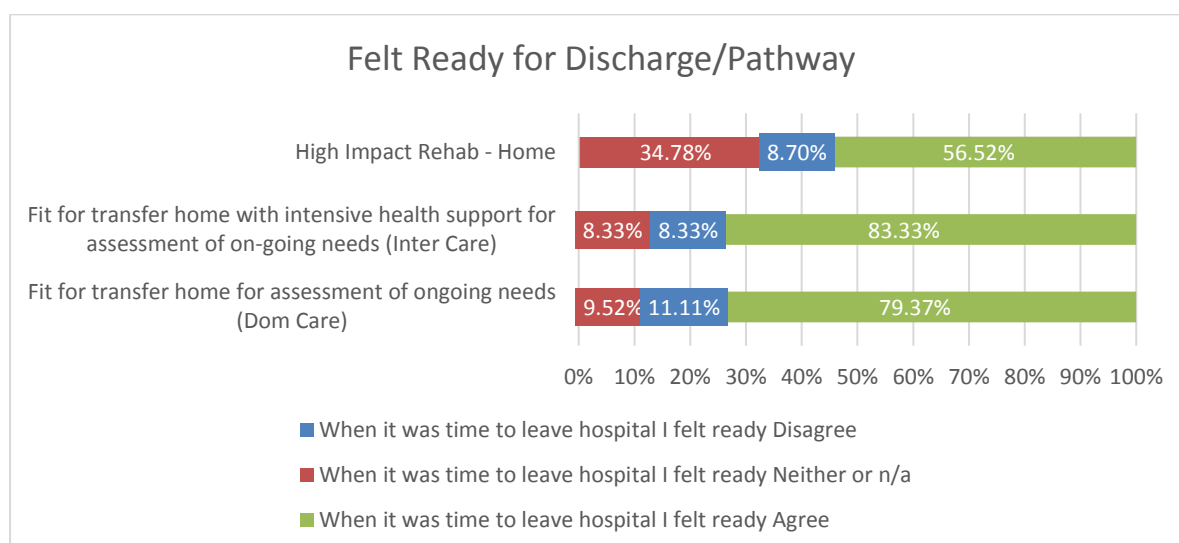
- **Pathway 3a - High Impact Rehabilitation - Home**

This pathway should be used for patients who are unable to be supported by primary care services at home but require on-going therapy or nursing treatment and care whilst undergoing assessment for their longer-term needs. This bed based service will focus on high impact therapy input and the aim for these patients will still be to get them home with support.

- Pathway 1- 63 (46.7%)
- Pathway 2- 48 (35.6%)
- Pathway 3a- 24 (17.8%).

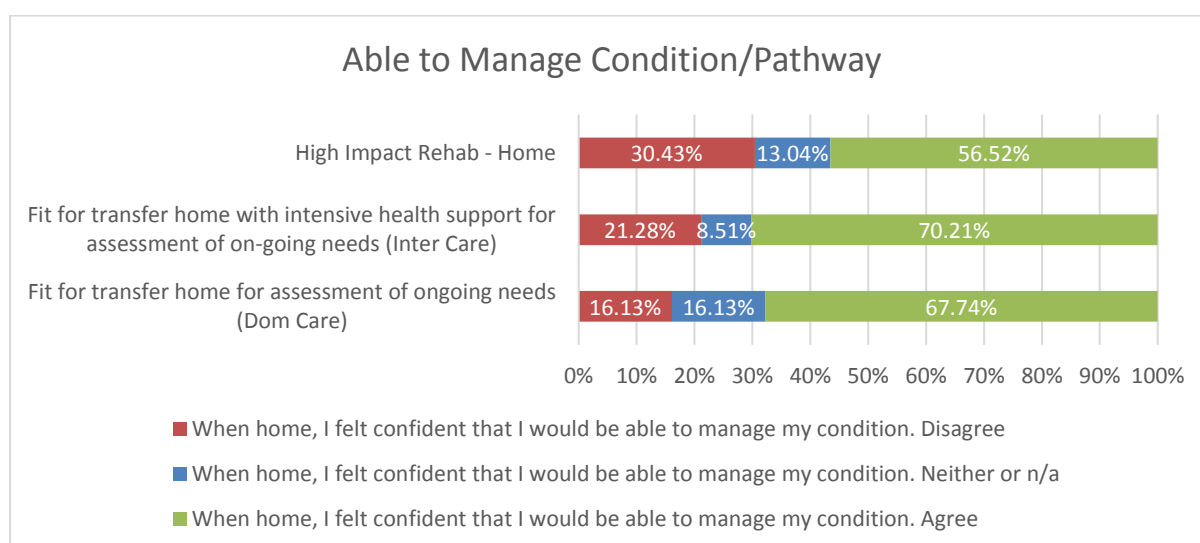
⁴⁵ <https://www.gov.uk/government/publications/quality-standards-for-care-services-for-older-people>

How ready for discharge do people feel when using different pathways?⁴⁶



Those who were to receive high impact rehabilitation (3a) in the home felt least ready for discharge.

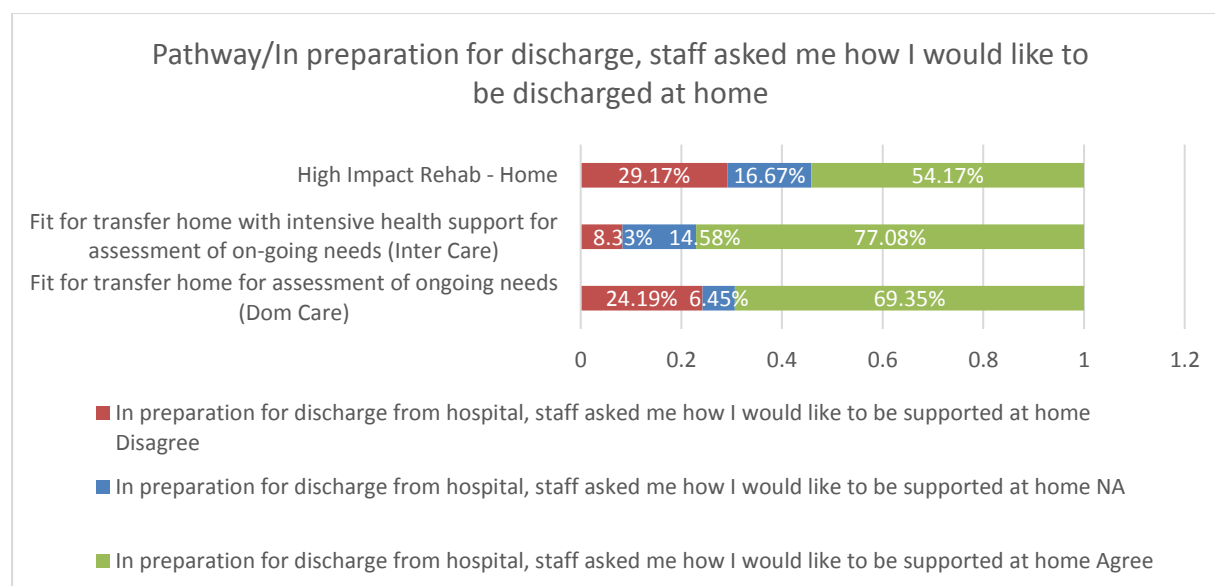
Do people feel able to manage their condition when using different pathways?



The data suggests some variation in confidence with those on the intermediate care pathway most so. Those in receipt of high impact rehab (pathway 3a) were least confident.

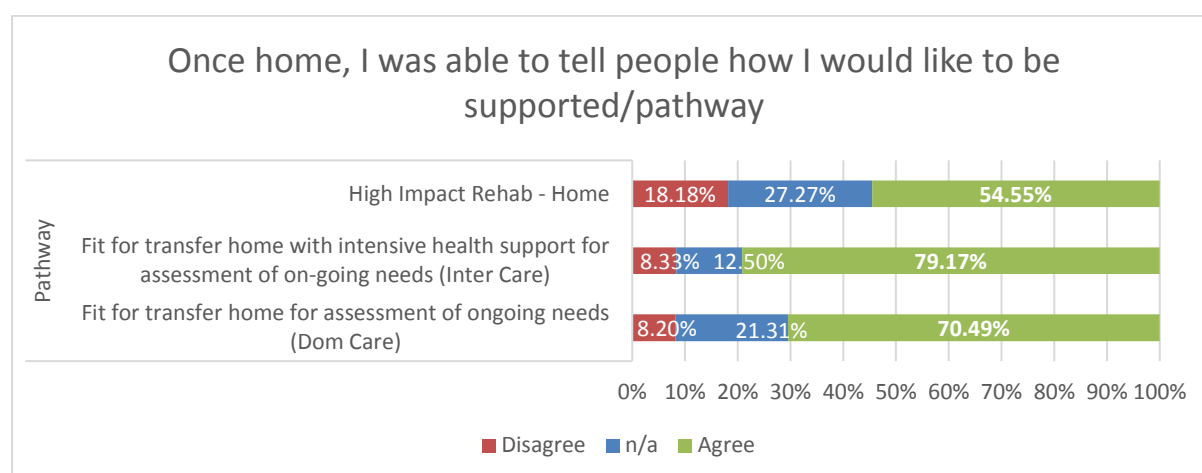
⁴⁶ Pathway A Domiciliary Care - 63 (46.7%) B Intermediate Care - 48 (35.6%) C - High Impact Rehab 24 (17.8%).

Did respondents on different pathways report differently about being asked about how they would like to be supported at home?⁴⁷



The data received indicates that those most likely to be asked about how they would like to be supported at home is those who are on the intermediate care pathway (2).

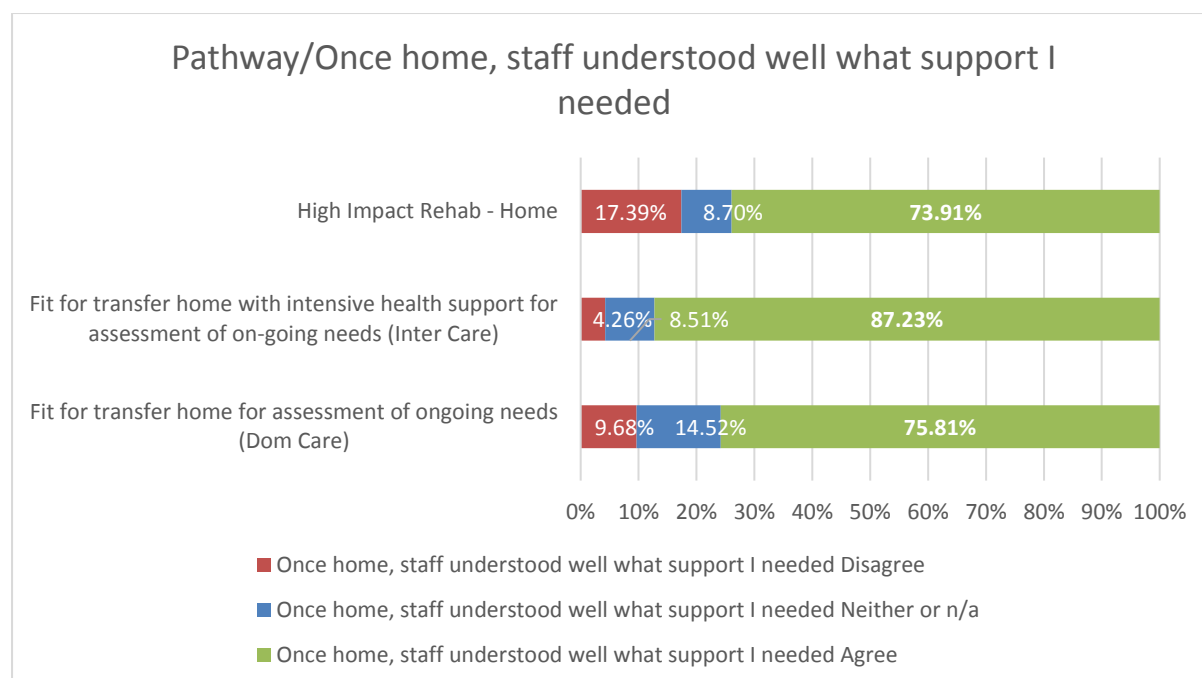
Were respondents on different pathways able to tell people how they would like to be supported once home?



The above indicates that those receiving high level impact rehab (pathway 3a) report being less able to tell people how they would like to be supported (18%).

⁴⁷ Pathway A Domiciliary Care - 63 (46.7%) B Intermediate Care - 48 (35.6%) C - High Impact Rehab 24 (17.8%).

Once home, did the patients on different pathways think that staff understood well what support they needed?⁴⁸



The above indicates that those receiving high level impact rehab felt that staff understood less (two-fold) what support they needed when compared with the other pathways.

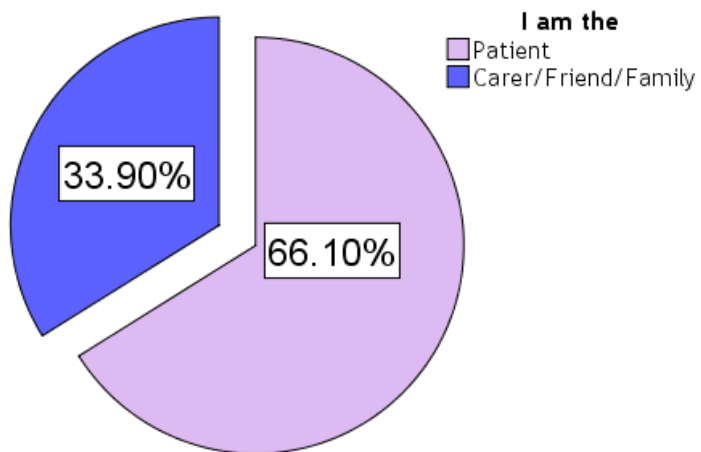
“Discharged about 5pm. Expected someone to come and put a care package together. Nobody came. The next day a person came to assess my condition and the following day hospital care and carers came. Fortunately, my daughter was able to have time off to look after me until carers came as I live on my own. 39 hours between discharge and having care is too long especially for those with no family and unable to shop for food etc.” - Pathway 2

⁴⁸ LOW NUMBERS - Pathway A Domiciliary Care - 63 (46.7%) B Intermediate Care - 48 (35.6%) C - High Impact Rehab 24 (17.8%).

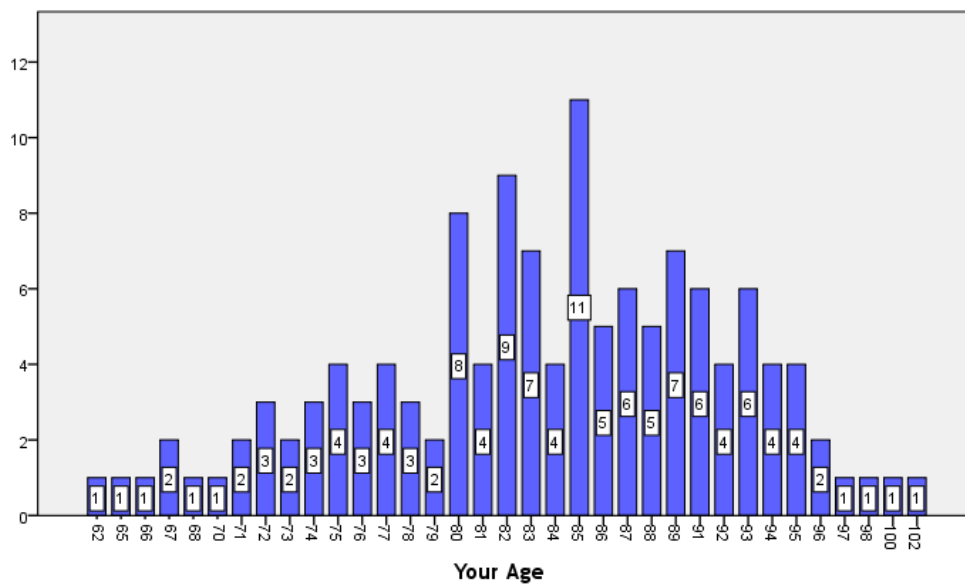
Results in Full

Q1 - I am the patient or carer/family/friend.

- Patient n=78
- Carer n=40



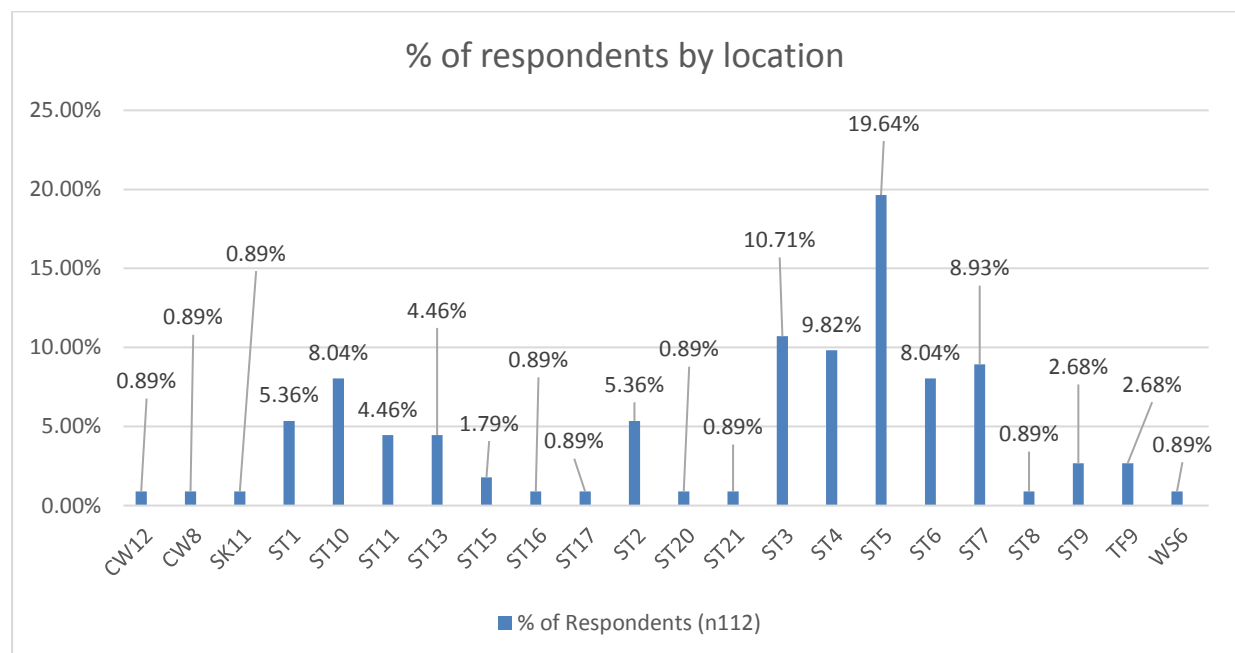
Q2 - Patients Age



Although some below the age of 75 did respond, the average age is 84.

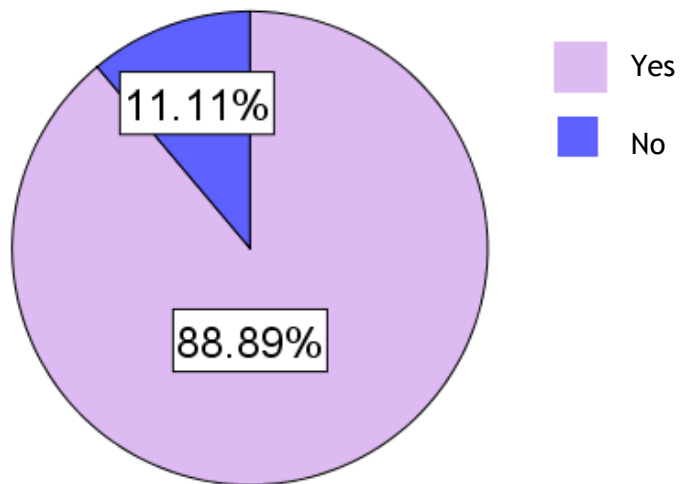
Q3 - Patient Location

109 respondents shared the first part of their postcodes. This distribution suggests that respondents would receive social care from different providers.



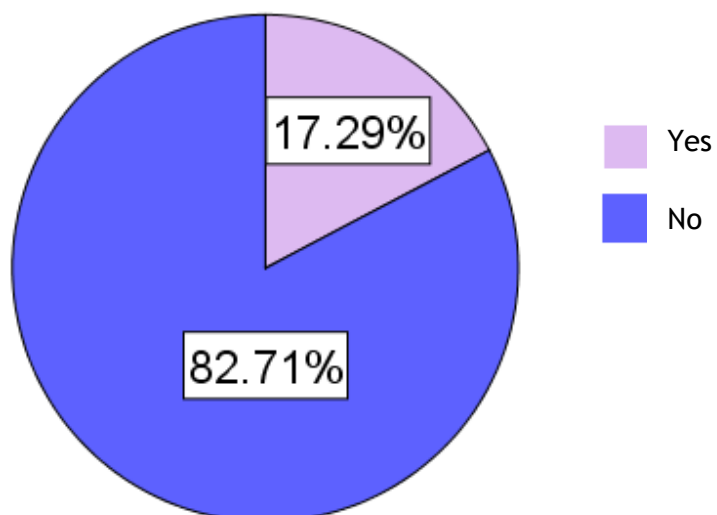
Q4 - Have you been in hospital, or have you cared for someone in hospital for more than once in the last 5 years?

- Yes n=120
- No n=15



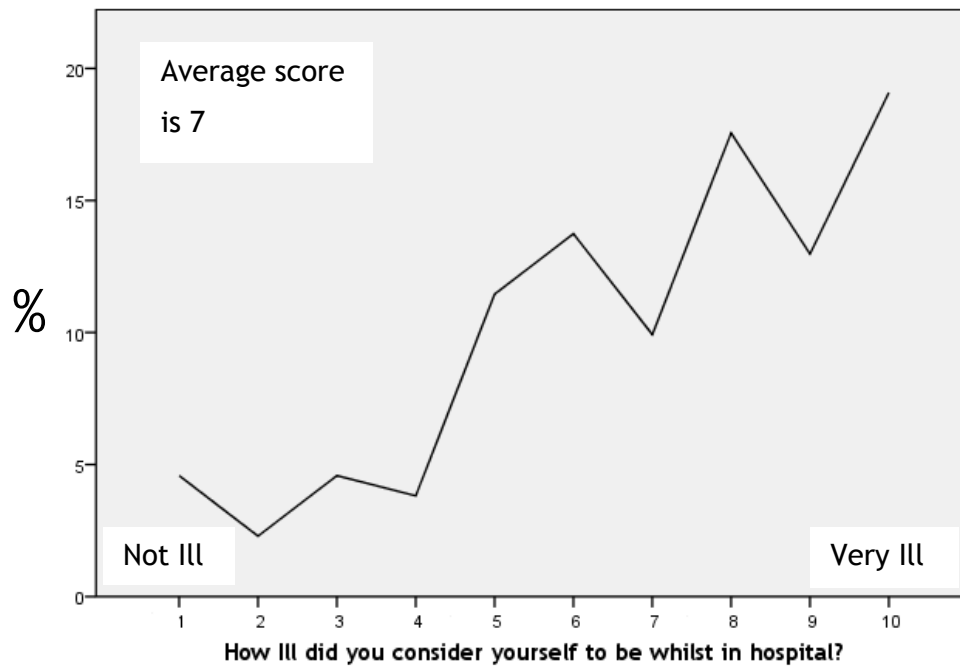
Q5 - Was your time in hospital planned?

- Yes n=23
- No n=110



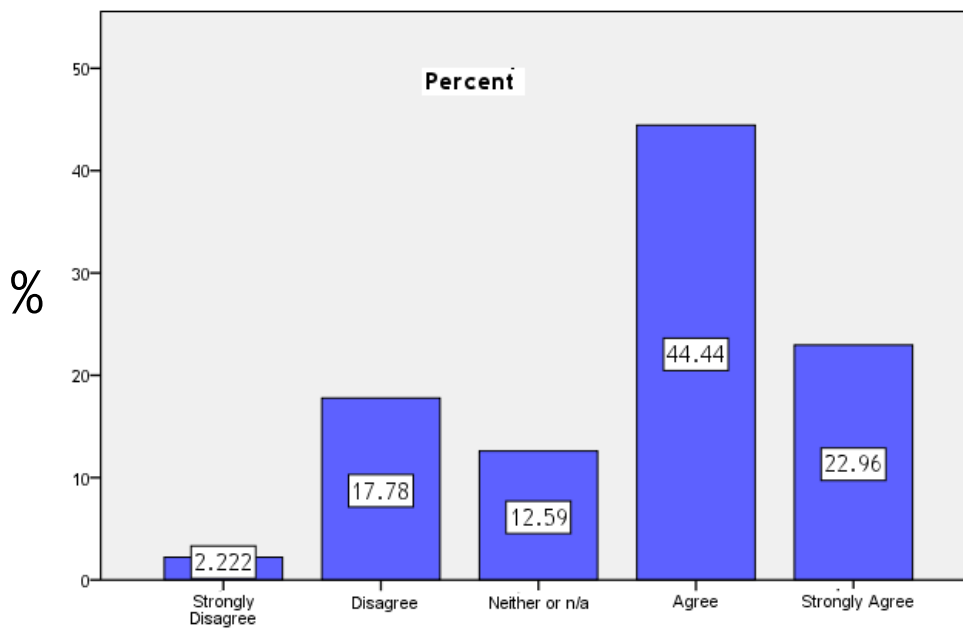
Q6 - How ill did you consider yourself to be whilst in hospital?

How Ill did you consider yourself to be whilst in hospital? Percent



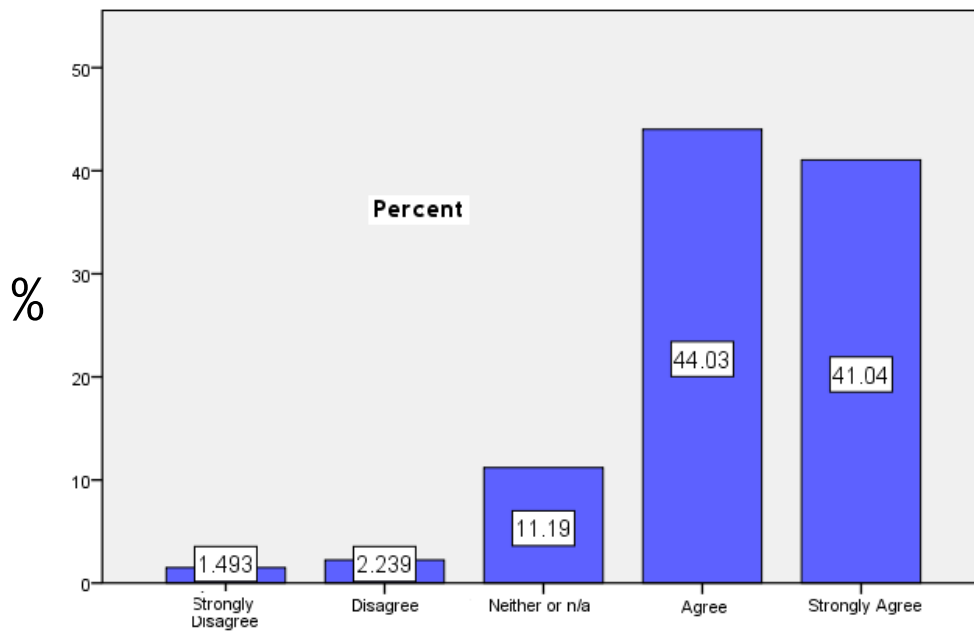
Q7 - Whilst in Hospital, I knew what was going to happen to me.

Whilst in Hospital, I understood well what was going to happen to me



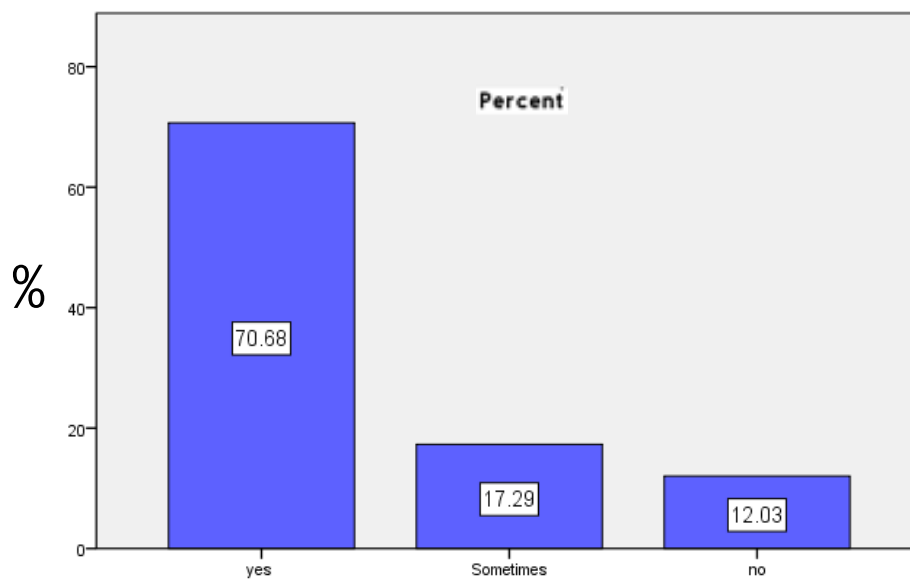
Q8 - I am the kind of person that likes to be involved in the arrangement of my care.

I am the kind of person that likes to be involved in my care



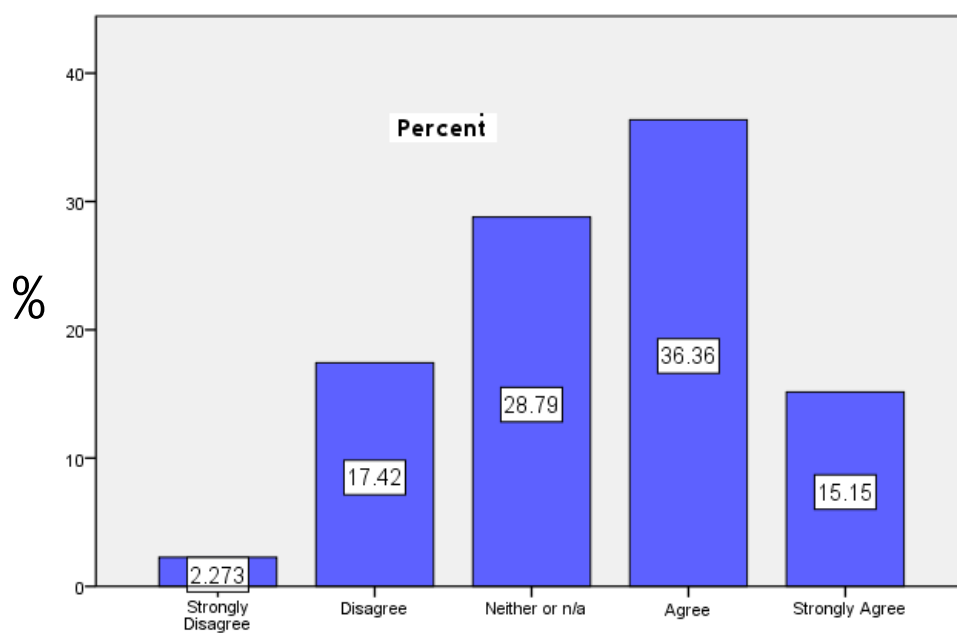
Q9 - Did you have a friend or family member that asked questions on your behalf?

Did you have a friend or member of the family who asked questions on your behalf?...



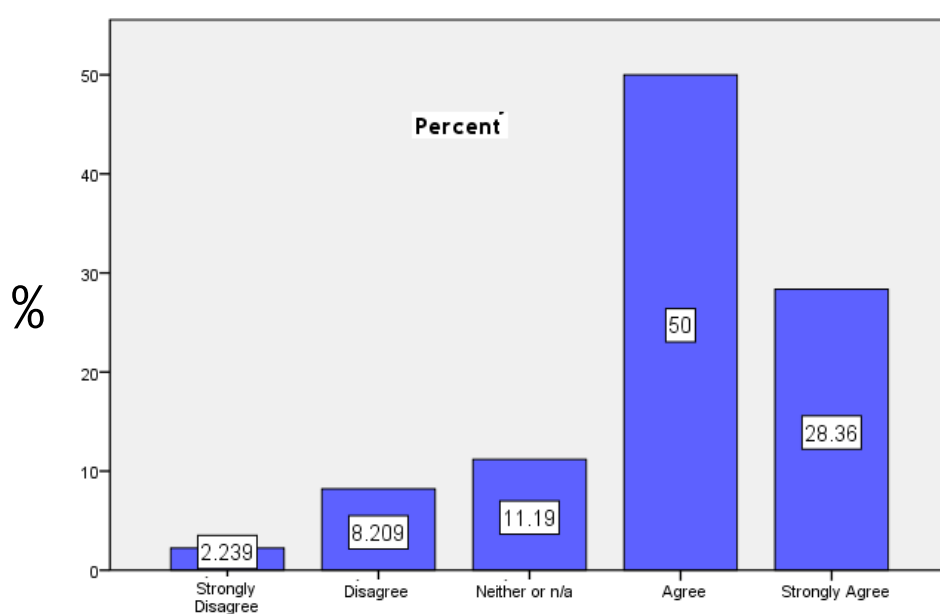
Q10 - Whilst in hospital I was encouraged to ask questions about my care.

Whilst in hospital I was encouraged to ask questions about my care.



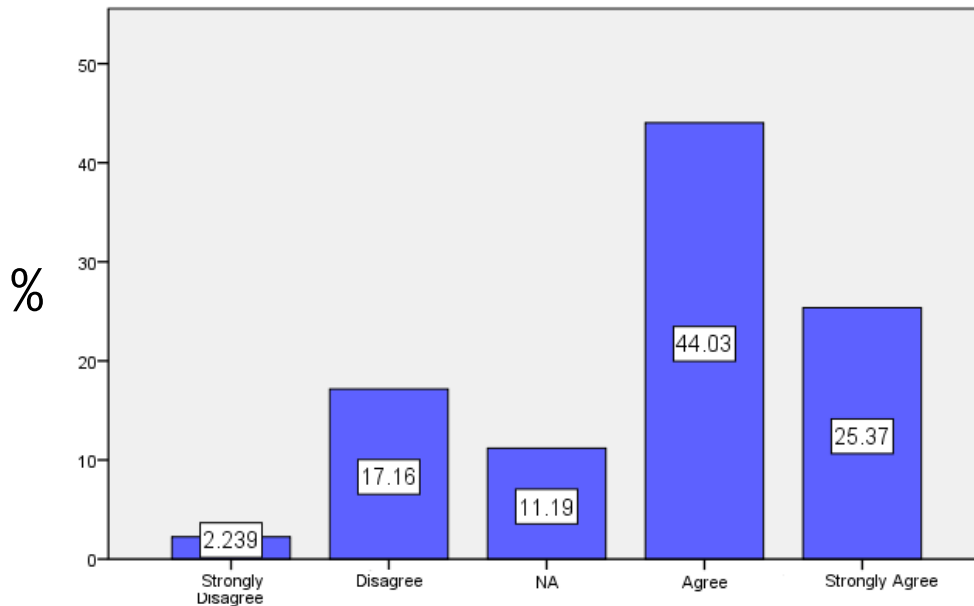
Q11 - I found it easy to approach hospital staff.

I found it easy to approach hospital staff



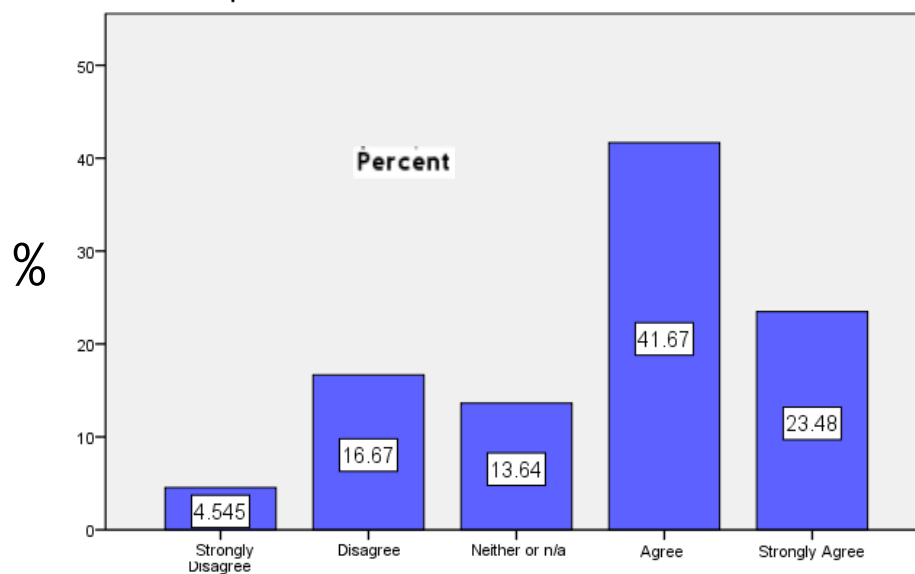
Q12 - In preparation for discharge from hospital, staff asked me how I would like to be supported at home.

In preparation for discharge from hospital, staff asked me how I would like to be supported at home...



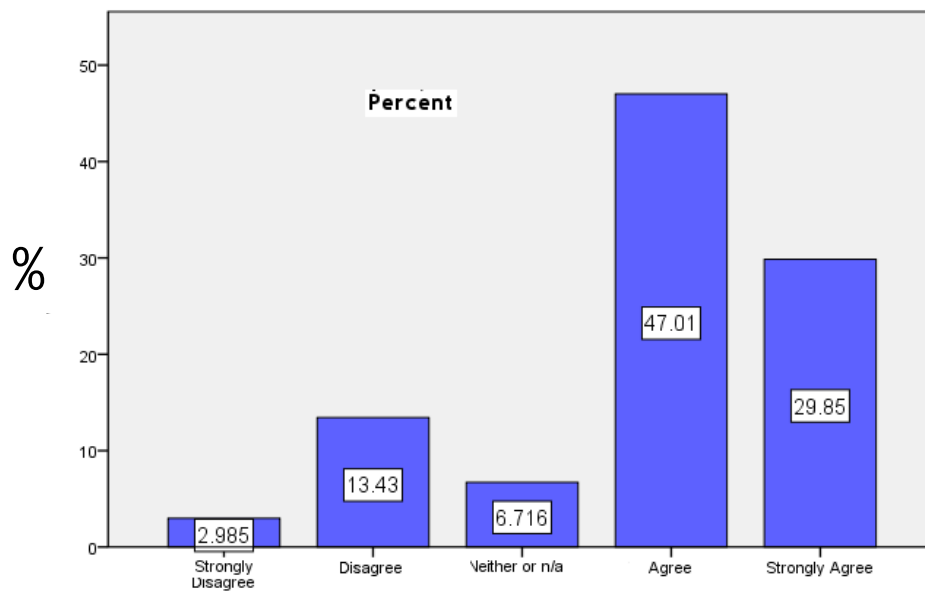
Q13 - Staff gave me clear, easy to understand instructions about my medication before I left hospital.

Staff gave me clear, easy to understand instructions about my medication before I left hospital....



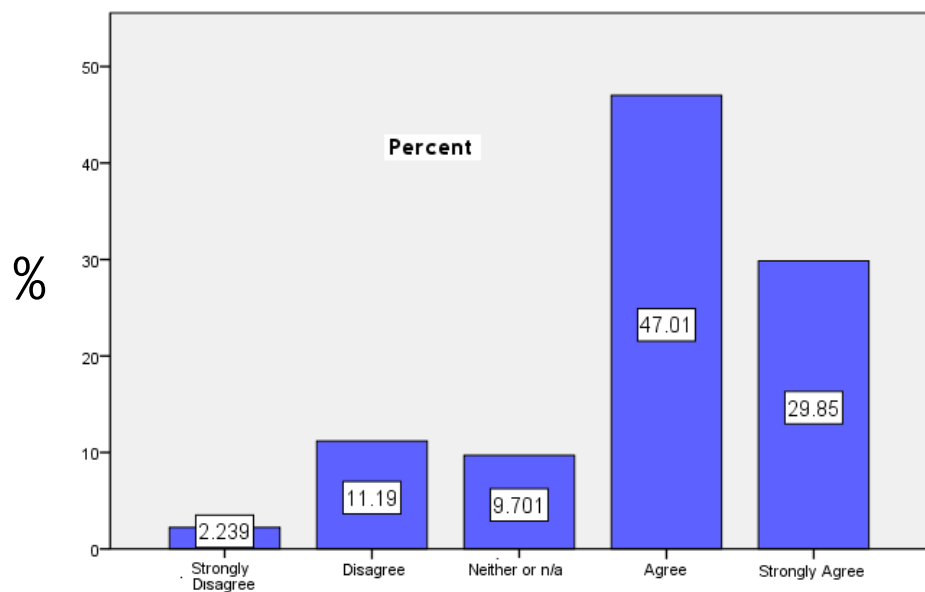
Q14 - In hospital, staff understood well what support I would need at home.

In hospital, staff understood well what support I would need at home

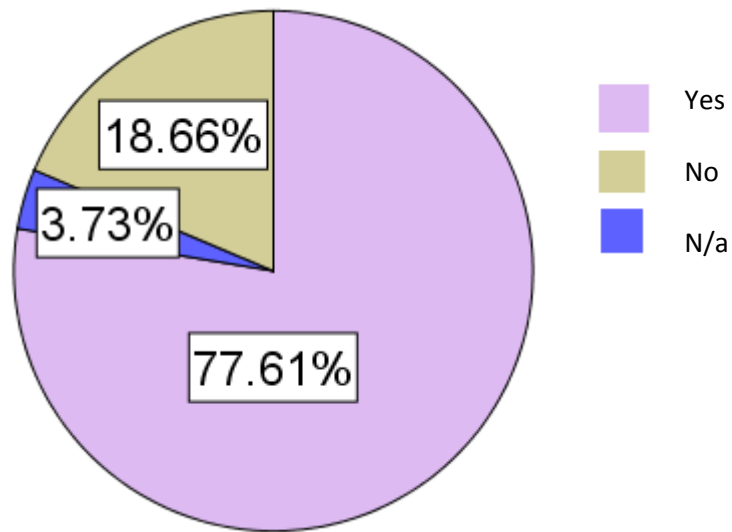


Q15 - When it was time to leave hospital, I felt ready.

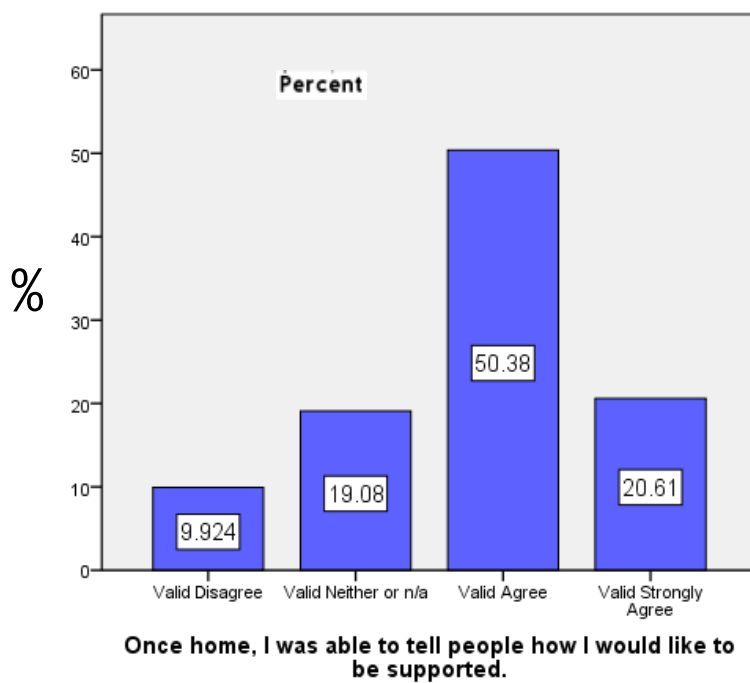
When it was time to leave hospital I felt ready



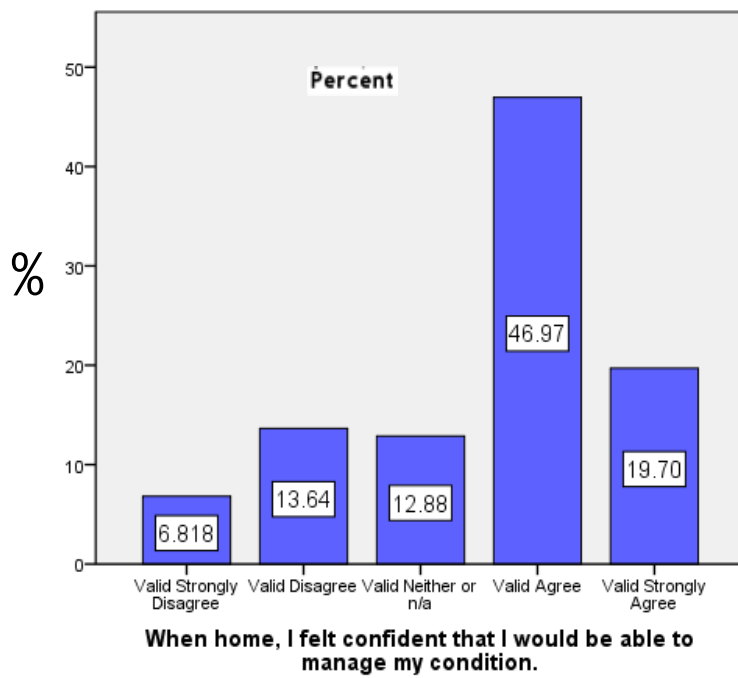
Q16 - Once at home I knew who to contact about my care plan or services.



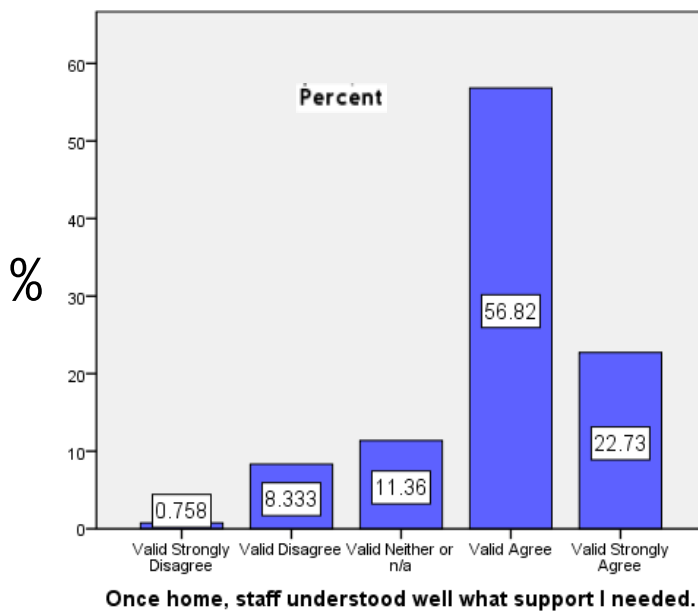
Q17 - Once home I was able to tell people how I would like to be supported.



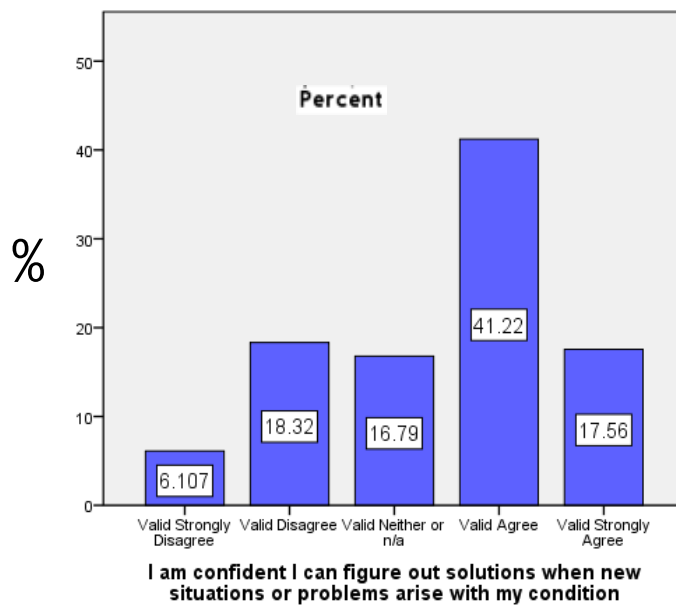
Q18 - When home, I felt confident that I would be able to manage my condition.



Q19 - Once home, staff understood well what support I needed.



20 - I am confident I can figure out solutions when new situations or problems arise with my condition.



Respondent Comments by Theme

Positive Comments - Staff

- **Pathway 1** - Very satisfied with care of all staff.
- **Pathway 1** - I was very impressed about everything about the treatments received and had carers for six weeks when returned home. They were excellent. I was in intensive care for 2 weeks I am very fortunate to be here. Mr(DR) was marvellous to save me. I had an aortic aneurism - good luck and continue the good work.
- **Pathway 1** - Always treated with the best of care.
- **Pathway 2** - Social Service, Therapy care staff, all helpful in hospital and at home.
- **Pathway 2** - The hospital staff, from the highest to the general nurses, porters, cleaners tea ladies, cleaners, brilliant!
- **Pathway 2** - Nurses who attended me gave support and advice when needed.
- **Pathway 2** - While I was in hospital all the staff were very kind, especially in ward 108 the sister was brilliant!
- **Pathway 2** - I had excellent treatment and care when I broke both my legs in my leg in sept 2016 after falling at home. I had 3 ops and spent 1 month in hospital (2 periods). The care continued when I went home.
- **Pathway 2** - I would like to thank Mr Patel for doing my knee operation, nurses and physio.
- **Pathway 2** - Without all the care of all the NHS staff I would now be dead. Thanks to all of you for help and service.
- **Pathway 3a** - I am the patient's niece have answered this on her behalf. She has bipolar, Alzheimer's, dementia and is unable to walk and is in a nursing home. She was treated very well in hospital and discharged to an appropriate place. She is unable to answer these questions.
- **Pathway 3a** - The staff in the hospital were brilliant. I was looked after and treated with care. I was not asked about aftercare but I thank them for looking after me.
- **Pathway 3a** - I am extremely grateful for the excellent care I received in hospital. I could find no fault in the service. Nothing was too much trouble and I was seen immediately. Thank you very much.
- **Pathway 1** - Hospital staff were outstanding as were social services team on my discharge.

Positive Comments - Various

- **Pathway 1** - Homecare package already in place.
- **Pathway 1** - My father felt very well supported by members of the care team once he left hospital. He was able to regain his confidence after being physically and emotionally exhausted. Thankyou
- The more senior hospital staff displayed in GENERAL, higher order communication skills such as questioning, clarifying esp the surgeons immediate team & wonderful critical care team. 3 - Discharge process very challenging, long wait having left ward to go to discharge lounge - waiting for medication in particular. DL was freezing and (illegible) for at least two hours.4 - Ambulance staff were exemplary
- **Pathway 1** - I did not know what medication I was given. I have very poor eyesight
- **Pathway 1** - My dad doesn't acknowledge that he needs help. He believes that he is well and comfortable at home and able to care for himself. The family appreciate the fact that hospital staff fully included him in decisions made about dads welfare and safety.
- **Pathway 2** - I broke my hip falling in the hallway at home. The ambulance only took 5 minutes to arrive. I was quickly to Stoke hospital. I was very satisfied with the standard of food. My arrangements to come home were also met satisfactorily and nurses visiting me at home and the psychology (perhaps therapy?) was really good.
- **Pathway 2** - I received a total hip replacement operation sept 29th 2016. I am a widower. It was decided that living alone, I required an intermediate care plan. They took an extra 3 days to organise beyond my 'normal' 3 day discharge date. That extra 3 days made ALL THE DIFFERENCE to my full recovery. Patients are discharged too soon. Care team Excellent but clearly under pressure.
- **Pathway 3a** - After leaving hip replacement surgery my husband was discharged to a local cottage hospital where he received intensive physio and rehabilitation. This led him to be more confident with mobility when he later came home. If this had not been available as is now the case, his prognosis would not have been so positive. he would also struggle / be unable to manage without my care at home even with home help visits.
- **Pathway 3a** - Home care plan and support good.
- I was discharged with an EDST very positive.

Negative Comments - Social Care

- **Pathway 1** - Social services came 2 weeks was not long enough. Due to funding they could not help for longer. Family had to help, would not of managed if had no family to help
- **Pathway 1** -Whilst in hospital my mother was moved to several different wards because of the lack of beds. The last time she was put on ward 78 with mental health problems resulting in us (illegible) her home before social care package was acquired. Our experience with of social care I am afraid to say is in a very poor state which no fault can be put at the staffs feet.
- **Pathway 1** -My mum has dementia. When asked if she did her own shopping, cleaning and cooking she said yes. this was untrue. She was sent home without notice and we, the family had to arrange private support.
- **Pathway 1** -Aides needed never arrived and there is some confusion as to the area of Meir Heath comes under. One person arranged a visit and came, but on the phone, I was told they wouldn't come because she was not in the area. This confusing meant that I missed the aides visit, which my mother really needed (illegible) as she has short term memory problems.
- **Pathway 1** -The Care package that was placed for me I rejected. I decided to choose my own carer. this has been difficult but is now working well.
- **Pathway 1** -I was waiting for a care plan for 12 weeks. That was very frustrating and very unpleasant
- **Pathway 1** -Care plan took so long that I organised my own care
- **Pathway 1** -The care team that help me are really amazing, however, I would like to have total care in place for when I am next in because often when I come back home, the care team can't come to me straight away because my slot has been taken
- **Pathway 2** - Discharged about 5pm. Expected someone to come and put a care package together. Nobody came. The next day a person came to assess my condition and the following day hospital care and carers came. Fortunately, my daughter was able to have time off to look after me until carers came as I live on my own. 39 hours between discharge and having care is too long especially for those with no family and unable to shop for food etc.
- **Pathway 3a** - Information about attendance allowance given to me by one person only. I have been given the higher rate. This is a very important point, especially now with regard to social care. We have now arranged my own care.

Negative Comments - Communication

- **Pathway 1** - Communication all along needs to be improved. Its ok to tell a patient they can go home, that's what they want to hear, but if no one discusses this with family how are they supposed to put things in place at home, especially if they live at home (the patient) and told patient can be discharged within hours. But will say shine clinic's invaluable, nothing was too much trouble - At Stafford
- **Pathway 1** - Understanding foreign accents is a big problem so I misunderstood a lot of the nursing staff.

Negative Comments - Discharge

- **Pathway 1** - Sometimes you are discharged too soon, depending what your illness is.
- **Pathway 2** -The discharge lounge was very unfriendly, staff gave me a sandwich and that was the only contact I had with anyone in the 3 hours I was there as I had to stay in the women's and was not allowed to sit with the others who happened to be men. It was an awful experience after my operation and still not feeling very well. The carers were good but after ICT finished I am still waiting for the community physio/ OT in April.
- **Pathway 3** - Patient (name disclosed) discharge from the hospital was rushed district nurse not asked. Poor care to begin with. No contact numbers given. Complete shambles and extremely stressful for all concerned - Patient + Carers and Family!!
- **Pathway 3** - 3 big operations, very well looked after and cared for pleasantly and well. Last time in hospital - very very upset and hurt when I wasn't ready to come home, wanted me out with no notice for family to arrange care. Very difficult time for us all, couldn't understand all the broken promises and change in attitude.
- **Pathway 2** - Discharge from hospital was very rushed.
- **Pathway 3a** - Biggest problem, sent home early as no community beds to get back on feet before coming home. Was ok last year but not now and not safe to manage at home.

Negative Comments - Patient Concerns

- **Pathway 2** - I get sometimes frightened I am going to lose balance.
- **Pathway 2** - Could not fault my after-care team at all. Operations, hip replacement second time. Had fall at home broke the new hip & femur bone in my leg.
- **Pathway 2** - Pain walk
- **Pathway 3a** - A recent viral illness affecting my balance has strongly suggested that a night commode & walking frame both be provided. Upstairs and down for safety. Recent admission to hospital after falling.

Negative Comments - Medication

- **Pathway 1** - I think staff should of made it clear what my tablets were for and when I should be taking them and how long for.
- **Pathway 2** - With regards to medication the visiting nurse wrote out a timetable to able to understand it - ie - 2 X tabs, with 4 hour intervals, this was not the case, elderly patients have problems doing their meds this way. More care needs to be taken in this respect.
- **Pathway 2** - More information when leaving. I was not told about medication given as I left.
- **Pathway 3a** - When discharged from hospital, nobody went through medicines with my dad, mum or myself, just put in a bag and given to us. No fludrocortisone tablets given back to us. Rang hospital they said dad had been taken off them and not had them in hospital. We were very concerned as dad has to carry a card saying he is on those tablets and if he needs to come off them it should be done gradually. Dad was very ill at the time and was much worse when he was off the tablets. No explanation given by the hospital as to why he was taken off them.

Appendix

Pathways

Pathway 1 - Acute Medical Episode Complete - Fit to transfer home for assessment of on-going needs (Domiciliary Care).

This pathway will be utilized when it is identified that the patient can be safely supported by primary care within their own home setting but need assessment for on-going support from domiciliary care services.

Pathway 2 - Acute Medical Episode Complete - Fit to transfer home with intensive health support for assessment of on-going needs (Intermediate Care)

This pathway should be used for patients that can be safely supported by primary care (GP's etc) within their home setting but require further support from health and social care teams to reach and maintain an optimum level of recovery. The model will align to the intermediate care model as described within NSF Older People, which includes on-going assessment by the multi-disciplinary team to determine long term needs. This may include a care package, on-going District Nursing or Community Matron case management.

Pathway 3 Acute Medical Episode Complete - Fit to transfer to bed based facility for assessment of on-going needs (Bed Based)

3a) High Impact Rehabilitation - Home

This pathway should be used for patients who are unable to be supported by Primary care services at home but require on-going therapy or nursing treatment and care whilst undergoing assessment for their longer-term needs. This bed base service will focus on high impact therapy input and the aim for these patients will still be to get them home with support.

Questionnaire

My Care My Way Project

This questionnaire is intended for people who are over 75 and have been discharged from hospital (any) over the last 18 months.

I am the . .

Patient

Carer/Family/Friend

Patients Age

First Part of
Patient's Postcode

Have you been in hospital, or have you cared for someone in hospital more than once in the last 5 years?

Yes

No

Was your time in hospital planned?

Yes

No

How ill did **you** consider yourself to be whilst in hospital?

Not ill

Very

1 2 3 4 5 6 7 8 9 10

“Whilst in hospital, I understood well what was going to happen to me.”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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“I am the kind of person that likes to be involved in the arrangement of my care.”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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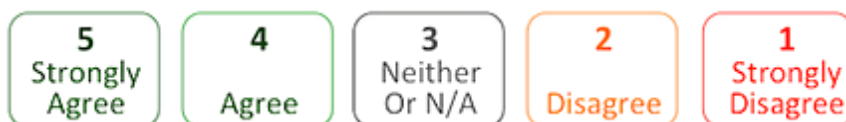
Did you have a friend or member of family who asked questions on your behalf?

YES	Some of the time	No
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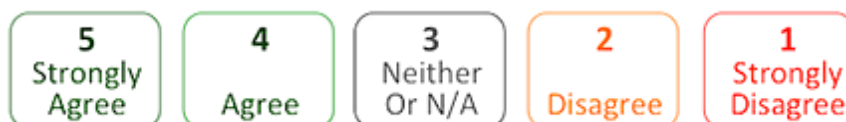
“Whilst in hospital, I was encouraged to ask questions about my care”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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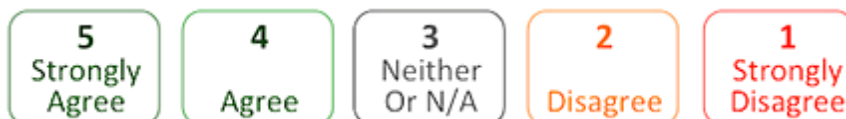
“I found it easy to approach to hospital staff”



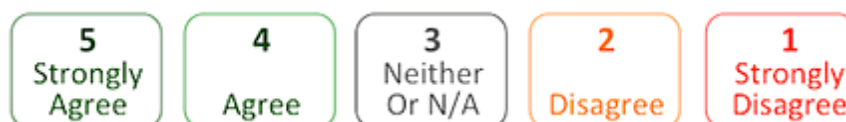
“In preparation for discharge from hospital, staff asked me how I would like to be supported at home”



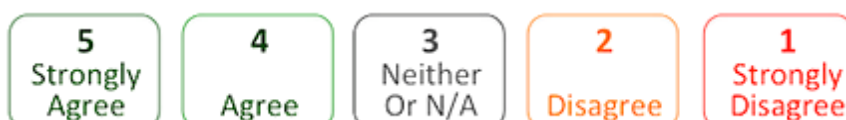
“Staff gave me clear, easy to understand instructions about my medication before I left hospital”



“In hospital, staff understood well what support I would need at home”



“When it was time to leave hospital, I felt ready”



“Once discharged (at home) I knew who to contact about my care plan or services”

YES	N/A	No
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“Once home, I was able to tell people how I would like to be supported.”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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“When home, I felt confident that I would be able to manage my condition”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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“Once home, staff understood well what support I needed”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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“I am confident I can figure out solutions when new situations or problems arise with my condition”

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
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Please write anything you would like to add in this box.

Any more information here