

July 2019

healthwatch

NHS Long Term Plan

Area Reports

Bedford Borough,

Central Bedfordshire

Luton and

Milton Keynes

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Bedford Borough

Background

Bedford Borough is dominated by the county town of Bedford that, with adjacent Kempston, makes up the Bedford urban area, which is surrounded by a rural area with many villages. Two-thirds of the population live in the urban areas of Bedford and Kempston, and a third live in the surrounding rural areas. More than one in three people in Bedford and Kempston are from minority ethnic groups, compared with fewer than one in eight in rural areas. Up to 100 different ethnic groups live in Bedford Borough, which means there are over 120 spoken languages and dialects. Bedford Borough ranks 148 out of 326 local authorities in England for deprivation; however, this average ranking masks pockets of significant deprivation that fall within the 30% most deprived areas in the country¹. The population age structure is similar to England overall, with 23% aged under 18 and 17% aged 65 and over; average life expectancy is also similar to the England average, although there are large inequalities in life expectancy depending on where people are born².

Summary of findings

What matters most to people in Bedford Borough?

Healthy life



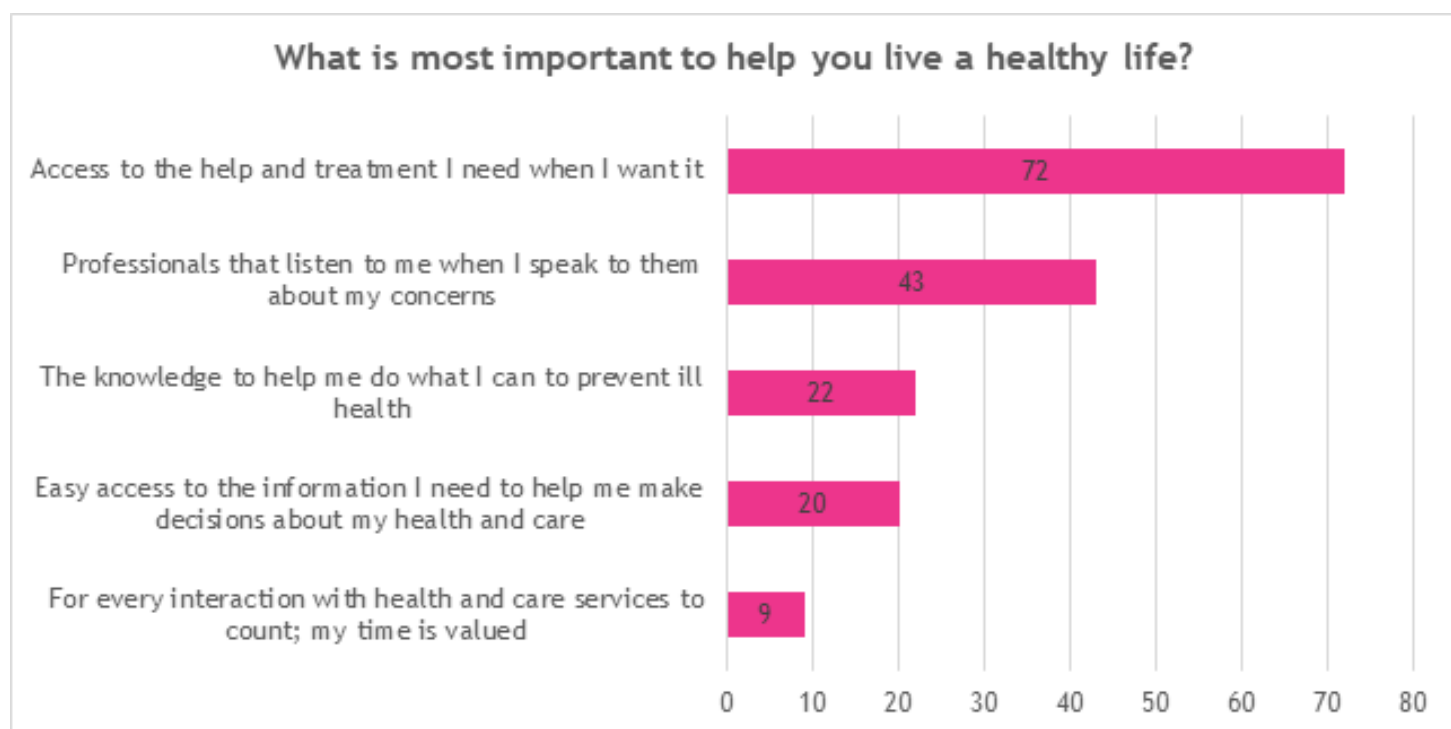
Over two in five people (43%) from Bedford said that ‘access to the help and treatment I need when I want it’ was the most important of the five statements shown in the chart below in helping them to live a healthy life. This was also the most important factor for people with a long-term health condition too, but only just above ‘professionals that listen to me when I speak to them about my concerns’, with 33% and 31% respectively. However, people see all of these statements as important. When survey respondents were asked to rate the importance of each of these statements, most people said each statement was important or very important with the percentage ranging from 91% to 100%.

¹Bedford Borough, Joint Strategic Needs Assessment, available at:

[https://bbcdevwebfiles.blob.core.windows.net/webfiles/Files/12a_Appendix A - JSNA Summary 2017.pdf](https://bbcdevwebfiles.blob.core.windows.net/webfiles/Files/12a_Appendix_A_-_JSNA_Summary_2017.pdf)

²Public Health England, Local Authority Health Profiles, Bedford, available at:

https://fingertips.phe.org.uk/profile/health-profiles/area-search-results/E06000055?place_name=Bedford&search_type=parent-area



Suggestions from survey respondents for what more could be done to help people live a healthy life centred around better access to professionals and services, particularly GPs, and access to information so people could look after themselves. People also felt there was a need for better communication to create a greater awareness of those services that do exist. There were also requests for access to free gym or exercise facilities, and regular screening and health checks.

"If I can see a health professional out of working hours. I need to take a day off from work to see a health professional and then that appointment is often cancelled."

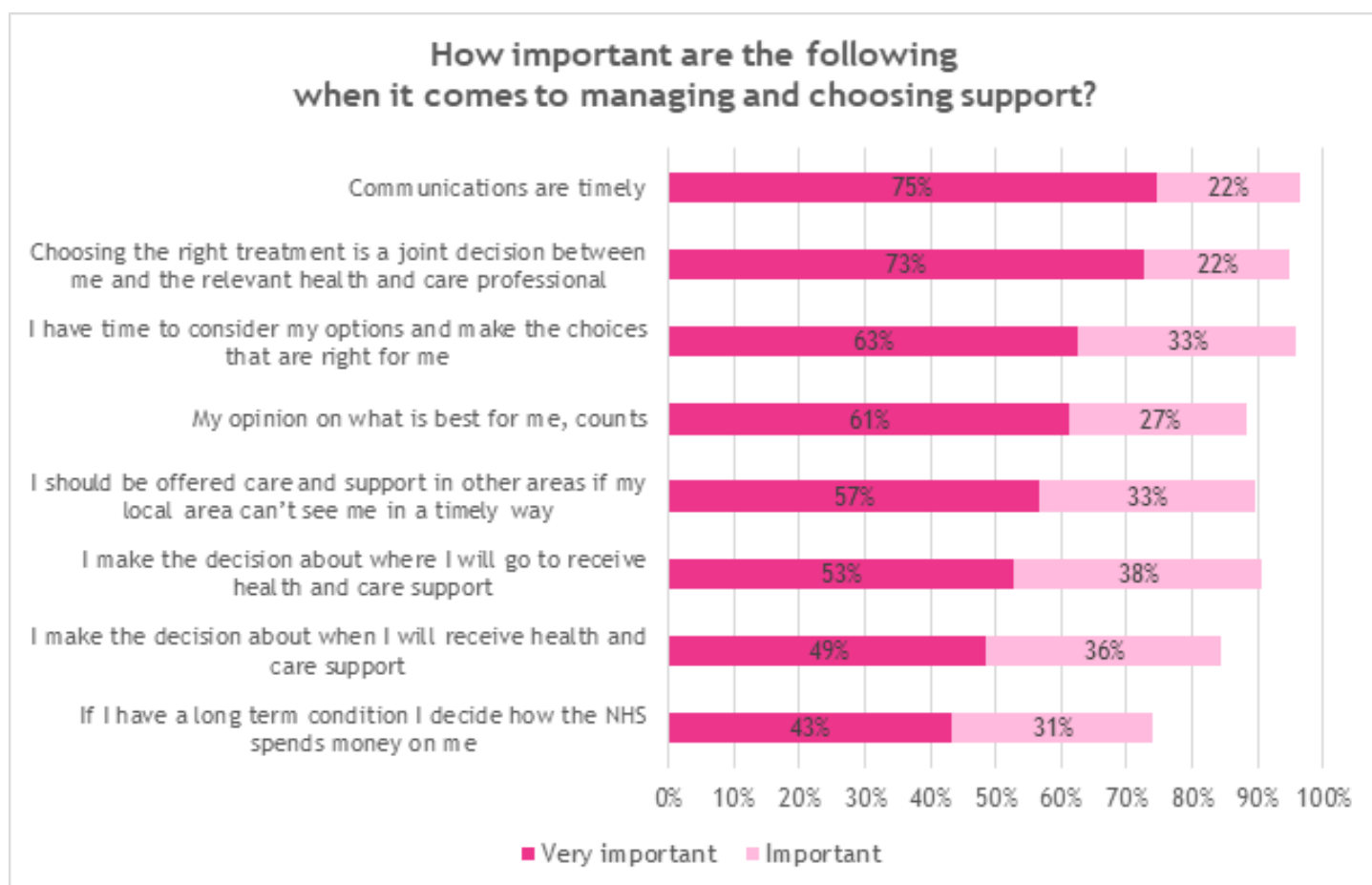
"Faster access to medical professionals especially my GP, Nurse Practitioners and specialist consultants with time to talk to you."

"Guidance on self-efficacy and behaviour change in daily living, and the knowledge of where and how to get that support when required."

Manage and choose support

‘Choosing the right treatment is a joint decision between me and the relevant health and care professional’ was overwhelmingly seen as the most important statement for people in Bedford in being able to manage and choose the support they needed. Over half (54%) chose this option, with the proportion rising to 70% among people aged 65-74. People were then asked to rate the importance of each of these statements (on a five-point scale from ‘very important’ to ‘not important at all’). The percentage of people rating the statements as important or very important ranged from 74% for ‘if I have a long-term condition, I decide how the NHS spends money on me’ to 97% for ‘communications are timely’ (see chart below).

A common comment from survey respondents was that they wanted faster access to GP services. People saw a need for easier access to booking appointments, test results and their personal health records, and several wanted fully integrated health records. Better online access was suggested by some, while others cautioned that not everyone has access to smart phones and the internet. Linked with this was the desire for better access to information and guidance.



“Access to GP when required. This is difficult in my area.”

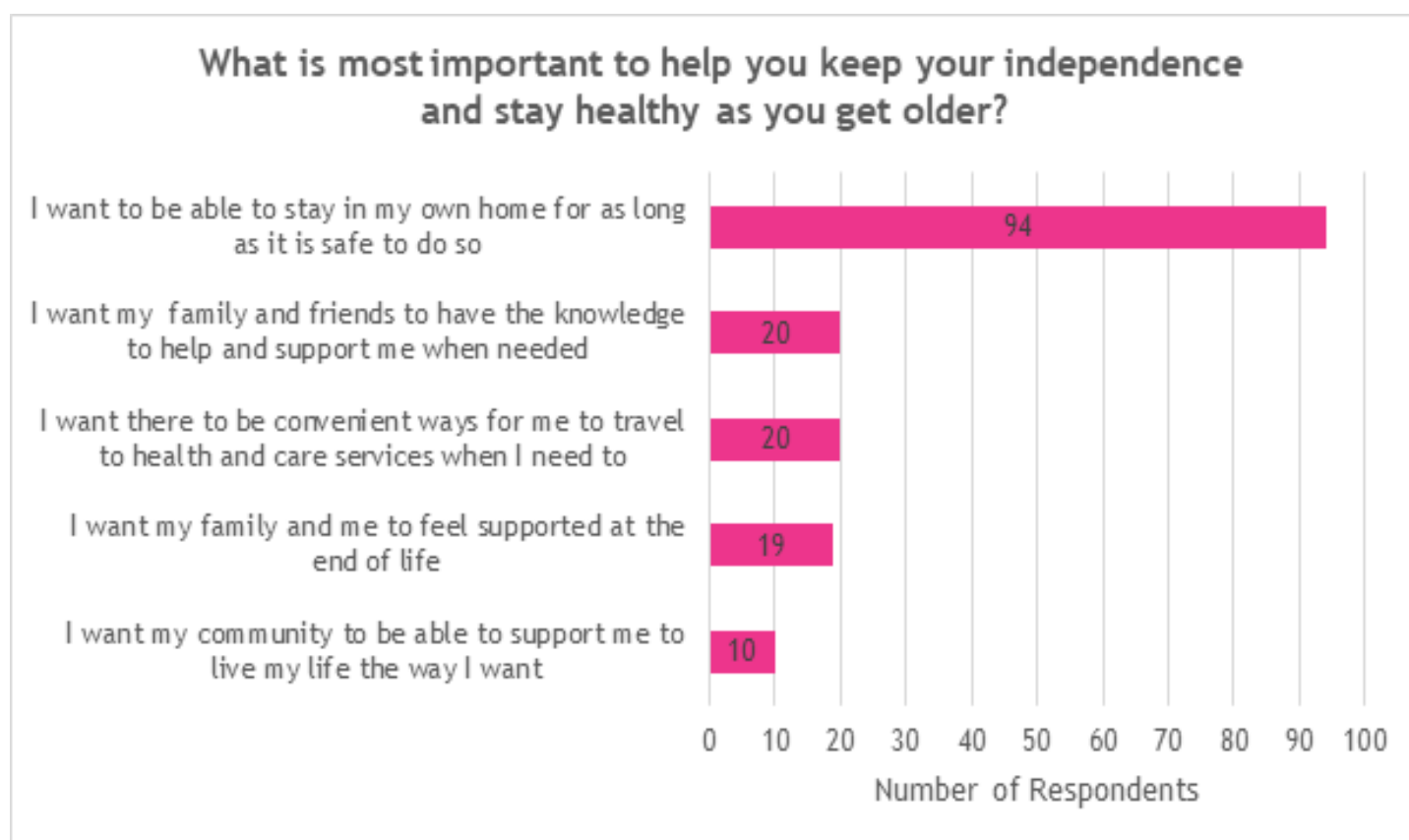
“Being able to email to get guidance, and my practice to reply to messages posted via the website - seems to be a black hole.”

“Easy access to the information I need, to help me make decisions about my health and care.”



Independence and staying healthy with ageing

People in Bedford attach a high importance to being able to stay in their own homes for as long as possible when they get older. Around 58% said it was the most important of all the statements shown in the chart below. The proportion generally increased with age: 44% of 18-54 year olds said it was the most important, rising to 76% of those aged 65-74 and 70% of those aged 75 and over. However, people attach a high importance to all the statements. When they were asked to rate the importance of each of the five statements (on a five-point scale ranging from 'very important' to not important at all'), the proportion that said each statement was important or very important ranged from 87% to 97%.



When people were asked for suggestions to help them retain their independence, affordable (or free) home care to enable them to stay living in their homes and community was high on the agenda. People wanted better care at home options, including more care in the community from specialist services, good district nurses, carers provided for basic help if required and increased support for unpaid carers. Secondly, they wanted to keep active and involved in the community - suggestions to enable them to do this included social groups (ideally free) and access to affordable exercise classes. They also saw transport to access services as being important, asked for more information on how to keep healthy, and wanted health and care providers to have a better awareness and understanding of their needs.

“Co-ordinated care package - everything seems to be fragmented at present.”

“Help with the little things in life by volunteers as it isn’t possible to keep paying out at the rate of £10 to £20 an hour for help with cleaning and gardening when you have long-term conditions like arthritis (can’t kneel) and diabetes.”

“I want access to sources of information that will help me keep independent and live healthily for as long as possible, such as information events/presentations, literature and online help.”

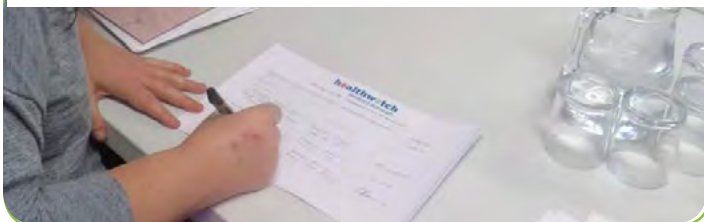


What did they tell Healthwatch?

Local engagement took place through three focus groups in Bedford Borough, attended by 33 people in total, and covering a wide age range from around age 18 to 90. The members of the general focus group were very well engaged, and quite vocal. The mental health group was pro-active, empowered and engaged throughout. The cancer group was small and more personal experience driven - they enjoyed sharing their own personal stories and hearing others' journeys but were less vocal and innovative than the other groups on potential commissioning changes they would like to see. Many useful suggestions were also received through the free format questions on the survey.

What works well?

- + There was a general consensus that there were examples of some superb GPs locally, with surgeries that have friendly and helpful staff, provide annual health checks and offer urgent same-day, as well as late evening, appointments. The Putnoe Walk-in Centre is also seen to be useful.
- + Cancer patients are generally content with the treatment packages they have received. Positive personal stories included quick identification and referral, no time pressures with the consultant or nurses at Bedford hospital, being offered mental health support, and good communication with Sue Ryder. However, experiences are varied regarding ongoing care.
- + Diabetic Retinopathy Service - can choose where to make an appointment, will explain what happens during your appointment and can provide an interpreter.



What could be better?

- + Access to services remain high on the agenda for people from Bedford Borough, particularly for non-English speakers and sensory impairment patients. A particular issue of concern is the major understaffing of the Speech and Language Treatment service for Special Educational Needs Children - for example, a child who is supposed to be seen three times a year has only been seen once in four years.
- + Basic health literacy is desperately lacking in Bedford Borough, which is impacting on choosing appropriate levels of care and the ability to live healthily as people get older. Health education is not consistent and is also needed from a young age. People wanted better signposting to reputable websites and sources of information.
- + Mental health provision needs to be a more holistic service, incorporating both physical and mental health as part of core evaluation. Prevention initiatives are also essential to improve quality of life outcomes. People felt that communication is lacking, especially during lengthy waits, and training is very poor across all areas in mental health.

Cancer health and care services

Cancer was one of the specific conditions agreed as a local objective, focusing on the three themes of: prevention; management - diagnosis and treatment; and aftercare and support. Of the 73 people from Bedford Borough who completed the condition-specific survey, 19 respondents referred to cancer with men outnumbering women. It should be noted that Bedford Borough does not have as many cancer support groups in the BLMK ICS footprint.

Prevention and/or early intervention

The focus group participants view earlier interventions as being essential and feel that more health education for the individual is needed. Overall, survey respondents are generally positive: just 3 of the 19 said that when they first tried to access help, the support did not meet their needs, and only two respondents said that the time that they had to wait to receive their initial assessment/diagnosis was slow or very slow. People's personal experiences are of course mixed - one had a very responsive GP, while another felt his GP lacked knowledge.

Assessment, diagnosis and treatment

Some members of the focus group have had a positive experience of diagnosis with good communication; others feel that the uncertainty at the beginning was unsettling and communication could have been better - both between the patient and health professionals, and among health professionals particularly when being referred to out-of-area specialists.

Survey respondents are generally positive about their experience after diagnosis: of the 19, 14 had been offered access to further health and care support after being diagnosed, all were referred to a specialist and only one said that the time they had to wait to see the specialist after their initial appointment was slow. People praised the nursing care, Macmillan, CLIC Sargent and stoma care support. There were only a few suggestions for improvement: some want access to more local therapy, and others would like better education, and more support and guidance.

The provision of ongoing care and support

The experiences of the focus group participants are varied regarding ongoing care. However, the consensus was that improvements are needed in aftercare, including follow-ups by GPs. Suggestions from survey respondents for improvement include more information on how diet and exercise may help, better training for GPs, and better education and awareness in schools.

"My GP was very helpful but possibly didn't know enough about prostate cancer. I found the delay in getting my biopsy results frustrating and worrying. At the initial meeting with the consultant he didn't explain things particularly well and I left feeling confused."

"Transport to London made it more difficult."

"It met all my expectations. I was treated with respect and we were given choices. There was no pressure to take up a referral."

Mental health services

The second specific condition agreed as a local objective was mental health, again focusing on the three themes of: prevention, management - diagnosis and treatment; and aftercare and support. Of the 73 people from Bedford Borough who completed the condition-specific survey, 26 specified a mental health condition. They covered a wide age range from under 18 to the 55-64 age group, and two-thirds were female. Again, this number is rather small for much detailed statistical analysis, but the comments provided by these respondents and the Bedford Borough focus group on mental health, which was attended by 15 participants aged 18-75, are valuable. It is particularly helpful to have the youth voice represented.

Prevention and/or early intervention

The overall view of the focus group is that more needs to be done on prevention and early intervention, which could greatly improve quality of life outcomes. They feel that early intervention is needed at grass roots level and that support tends to be aimed at severe conditions rather than early intervention. They also commented that there is a lack of awareness of mental health in GP practices and mental health training is required. The focus group contained some hearing-impaired participants who were concerned that staff at GP surgeries were not BSL friendly.

Results from the survey highlight long waiting times. Seventeen of the 26 respondents said that the time they had to wait to receive their initial assessment was slow or very slow; just two said it was fast or very fast. In addition, for 14 of the respondents, the support they received when they first tried to access help did not meet their needs; this compares with three who said it did, and eight who felt it somewhat met their needs. Survey respondents' comments about the support that was provided tended to be negative - they mentioned long waiting times, taking a long time to get on the pathway and a general lack of support.



Assessment, diagnosis and treatment

Some of the focus group have had positive experiences with individual GP surgeries and the Mental Health Wellbeing Service, but the majority had poor experiences with the unsettled nature of primary care and perceived poor training of local clinicians and staff, including a lack of cultural awareness. They are unhappy about the long waiting lists for counselling or CBT and also feel there is a need for information for parents/carers on how to support children/young adults while they are on waiting lists. One person discussed privately her range of concerns with acute mental health crisis services. Many survey respondents mentioned long wait times and limited options for support and advice. Of those that answered the question about the time they had to wait between initial assessment/diagnoses and treatment, fourteen said it was slow/very slow, four said it was OK and four said it was fast/very fast.

The provision of ongoing care and support

Focus group participants had similar comments about ongoing care and support as they did for assessment, diagnosis and treatment - some have experience of good GP surgeries while others feel that high staff turnover means that there was no relationship with support workers and lack of support. Results from the survey also highlight the difficulties in accessing ongoing support - fourteen said it was difficult/very difficult and five said it was OK - just two said it was easy/very easy. Aspects that the respondents felt worked well included art therapy, counselling (but not enough sessions) and group sessions. They wanted more long-term help, more explanations to help them understand and more deaf awareness.

“Contact/communication for deaf people to make appointments, e.g. telephone only (primary care)”

“No timely support available - felt lost and helpless as parents. Waiting lists way too long, no signposting in the meantime, so left struggling and wondering if we were doing the right thing while waiting to be seen by anyone”

“I want more long-term help instead of only a certain amount of sessions”

Engaging people in health service delivery

What people expect during their treatment journey

'I can talk to my doctor or other health care professional wherever I am' was rated by far the most important statement when interacting with the NHS - by 45% of people who answered the question. However, when respondents were asked to rate the importance of each statement (on a five-point scale ranging from 'very important' to 'not important at all'), 'any results are communicated to me quickly making use of technology' had the highest proportion saying it was important or very important (92%). Each statement in the chart was rated important or very important by at least three-fifths of those who responded.

What is most important when interacting with the NHS?



What works well?

- + There are some very good individual GP surgeries, but this needs to be consistent across the borough.
- + Putnoe Walk-In Centre was seen as a useful resource, as was the Urgent Treatment Centre (UTC) at Bedford Hospital, except for issues with onsite parking and local transport routes to the UTC.
- + Cancer patients are content with the treatment packages they receive.

What could be better?

- + Better access to mental health services and a more holistic service, incorporating both physical and mental health as part of core evaluation.
- + Improved access to GPs with extended opening hours, being able to talk to the GP on the phone and the ability to make timely appointments.
- + Speedier communication (including receiving test results) and better information so patients can make informed decisions.

What people expect during service change and transformation

Each of the focus groups in Bedford Borough asked people about when and how they wanted to be engaged about the plan.

When?

- + Answers ranged widely about how often people wanted to be consulted - from throughout the process to quarterly.

How?

- + Engagement should be as wide as possible.
- + Access seldom heard groups by going to them (for example, supermarkets).
- + Information on local radio or podcasts.
- + Youth peer teaching.
- + An inclusive mental health group with representatives from each community in the borough.
- + A youth mental health partnership board.
- + Commissioners attending the 'Working Together' People Participation mental health support group run by East London NHS Foundation Trust (ELFT) to actively get service users and carers perspectives and views.
- + The process should be humanised - more sharing stories and fewer tick boxes.
- + Feedback should be both directly to commissioners and to Healthwatch.

How the NHS can make care better for people with sensory impairment — Ciaran's story

An estimated 16,000 people in Bedford Borough have a moderate, severe or profound hearing impairment, only approximately 400 are registered as deaf or hearing impaired¹.

Ciaran is profoundly Deaf. He shares his views about what would make NHS services better for people with hearing impairment.

Better training of frontline NHS staff

"Living as a patient with profound Deafness can be a challenge for me at times. Having depression and social anxiety has meant frequent visits to local health services for me. I would like to see more training for staff in providing suitable environments for people with hearing impairment and better understanding of the needs of the Deaf population of Bedford Borough.

I want to be treated with respect and dignity, and listened to by those who are providing NHS services. I have had some wonderful care from dedicated caring staff, but there have been gaps in provision. Services such as mental health services are stretched very thinly. I would like to see more training for staff in recognising and working with people with profound hearing loss and providing suitable adjustments, such as hearing loops, paging systems and Level 1 BSL training"

Easier access to support

Finding information and support used to be a worrying and stressful process for Ciaran, before he met Healthwatch Bedford Borough through Hear Me Out and Access Bedford and used HBB's WhatsApp message service to gain access to support and guidance.



'Mainly I want professionals to see me as a patient first and not just see my disability'
Ciaran

"For vulnerable communities like mine, finding help can be even more difficult. It's vital that Deaf people shouldn't have to struggle to get to the help they desperately need and deserve. Why do we have to fight to get the same treatment as a hearing neighbour?"

Service delivery

With limited understanding of what would be deemed the most appropriate level of care, the Deaf population struggle to access equitable service provision.

"My family are extremely supportive in terms of my health, however as I am now a young adult, I would like to be able to take responsibility for my own health and wellbeing and be able to access services that hearing friends can. I think the NHS locally need to understand the impact that being made to have counselling with another stranger in the room has on my community. For me, I already have anxiety. This thought has doubled my anxiety levels. Let me ask the commissioner, would you want to have counselling with someone else sat in the room listening to your personal thoughts? No, didn't think so!"

Central Bedfordshire

Background

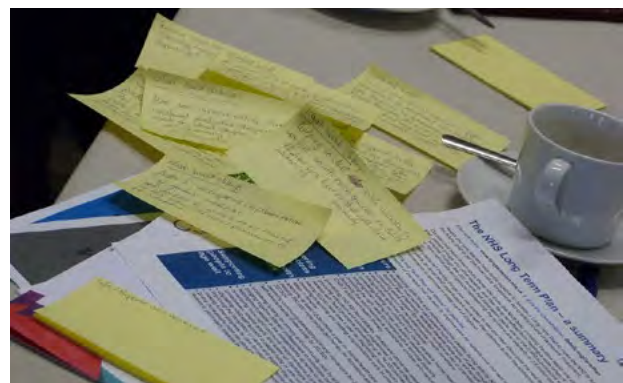
Central Bedfordshire is a mainly rural location in the East of England covering 716 square kilometres, with 58% of residents living in areas that are classified as rural³. The population age structure is similar to England overall with 22% aged under 18 and 18% aged 65 and over. The proportion of people from an ethnic minority group (8%) is well below the England average (14%). The health of people in Central Bedfordshire is generally better than for England overall. The proportion of children living in low income families (11%) is below the England average and life expectancy for men and women is higher than England overall⁴.

Summary of findings

What matters most to people in Central Bedfordshire?

Healthy life

Just over half (52%) of people in Central Bedfordshire said that 'access to the help and treatment I need when I want it' was most important of the five statements shown in the chart below in helping them to live a health life. For people with a disability the proportion was lower at 36% - they were equally as likely to say 'professionals that listen to me when I speak to them about my concerns' was the most important reason (36%). However, all these statements are important to people. For each statement shown in the chart below, over nine in ten people rated it as important or very important (on a five-point scale ranging from 'very important' to 'not important at all'). Survey respondents' suggestions for what would help them to lead a healthy life were mainly centred around better access to services, particularly more local services and mental health services. Other suggestions included more frequent check-ups, better information on how to live a healthy and active life and access to appropriate, and reasonably priced, facilities for exercise.

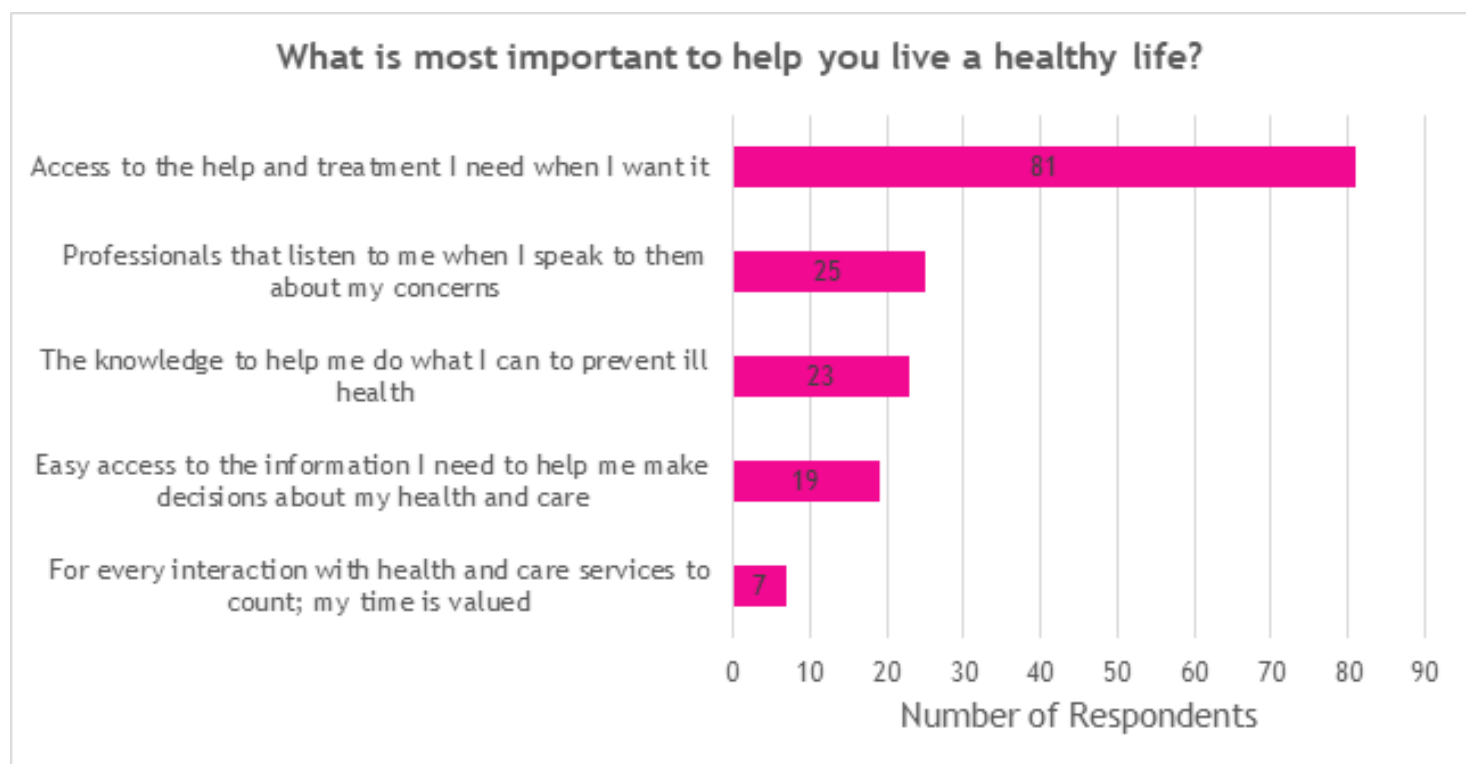


³Central Bedfordshire, Joint Strategic Needs Assessment, available at:

<https://www.jsna.centralbedfordshire.gov.uk/jsna/info/8/demography/48/population>

⁴Public Health England, Local Authority Health Profiles, Central Bedfordshire, available at:

https://fingertips.phe.org.uk/profile/health-profiles/area-search-results/E06000056?place_name=Central%20Bedfordshire&search_type=parent-area



“More accessible services for those who live in more rural areas where access can often be more restrictive and expensive.”

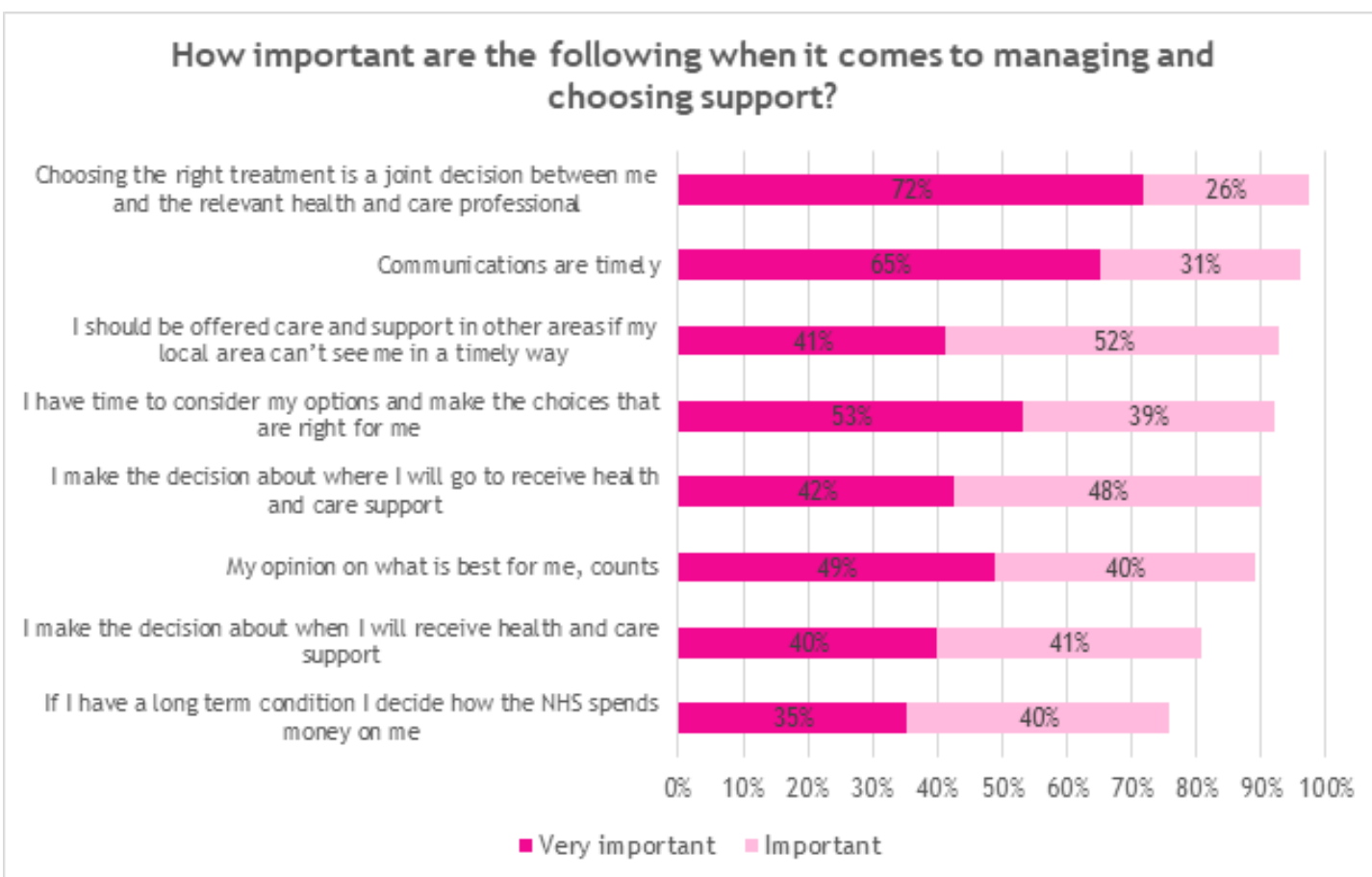
“Being able to get an appointment when you attend your local GP, also to have the knowledge of the community services available to you so that you could possibly refer yourself to.”

“Blood tests in house at GP surgery rather than having to go to a local hospital.”

Manage and choose support

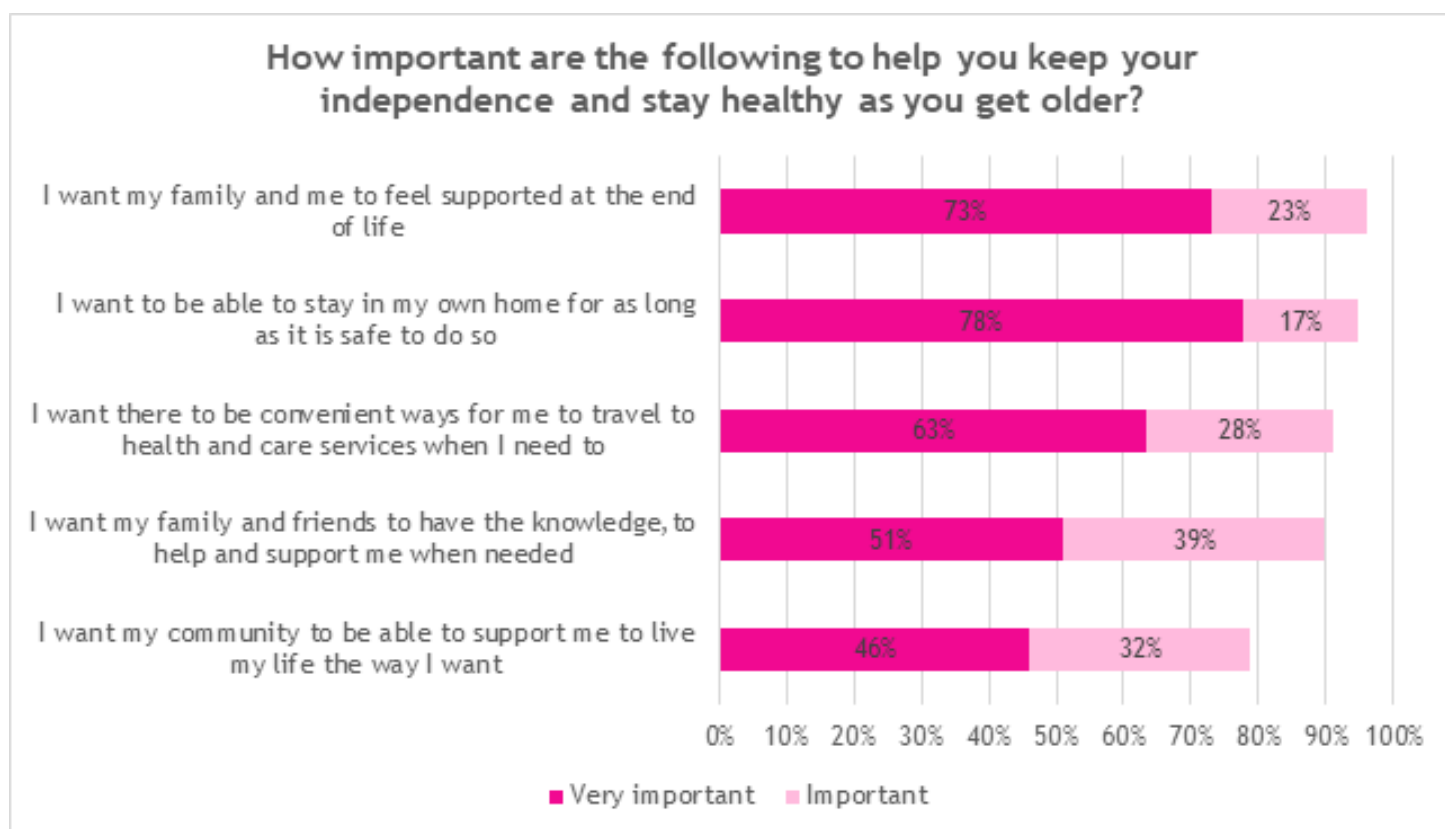
When asked about what is important when it comes to managing and choosing support, 72% of people in Central Bedfordshire who answered the question rated 'choosing the right treatment is a joint decision between me and the relevant health and care professional' as very important, and almost as many (65%) said 'communications are timely' was very important. People were also asked what they thought was the most important statement: almost half (46%) of respondents said that 'choosing the right treatment is a joint decision between me and the relevant health and care professional' was the most important of the eight statements.

Improvements suggested by survey respondents included: better communication (for example, being able to have discussions with professionals), a more holistic joined-up approach among health professionals and being more informed about options and outcomes. Suggestions for improvements from focus group participants echoed the call for improved communication between departments, and some people also wanted better availability of GP appointments. The use of technology divided people - some wanted more online services, others did not. It is important to remember that not everyone has access to technology or is comfortable using it.



Independence and staying healthy with ageing

People in Central Bedfordshire attach a high importance to being able to stay living in their own home for as long as it is safe to do so in order to keep their independence and stay healthy as they get older. Overall, 57% of survey respondents said it was the most important out of the five statements, and this rose by age to around seven in ten people aged 65 and over. People were then asked to rate the importance of each of these statements (on a five-point scale from 'very important' to 'not important at all'). Overall, 78% of people said 'I want to be able to stay in my own home as long as it is safe to do so' was very important and a further 17% said it was important (see chart below). A similar proportion of people (96%) rated 'I want my family and me to feel supported at the end of my life' as either important or very important.



Suggestions from survey respondents that they thought would help them to retain their independence centred around staying in their own home, including: the importance of a regular integrated public transport system in rural communities, access to clubs/group to prevent social isolation, and better (and affordable) home care services.

“The patient needs to be seen as a whole person with ALL their needs considered. It is no good separating health needs from social needs and it’s important to recognise that care at home goes far beyond healthcare and social opportunities. Any care package needs to include things like shopping, cleaning, laundry, cooking.”

“I don’t drive, and the public transport is quite limited where I am at evenings and weekends. If I have appointments in the week, they need to be within the times that the buses run, otherwise I have to get a taxi and that becomes very expensive.”



What did they tell Healthwatch?

Local engagement took place through three focus groups in Central Bedfordshire, attended by 44 people in total and covering a relatively wide age range from early 20s to mid 80s. Useful information was also received through the free format questions on the survey.

What works well?

- + Prevention, screening and public awareness schemes are valued by focus group participants. High profile promotion schemes, such as Stoptober and Dry January, are well received as they provide information as well as warnings. Preventative health screening is appreciated, and high-profile campaigns have worked well.
- + Community support from the voluntary sector - both national and local - works well. National high-profile organisations such as Macmillan, the British Heart Foundation and MIND provide valuable information, advice and support. Focus group participants have a good knowledge of the local groups that are available, including the locally run Good Neighbour Scheme that offers low level support. Voluntary transport was valued, not only for trips to the hospital/doctors but also for pleasurable trips out in the community.
- + People like the range of communication methods that are available. The online system for appointments and prescription is thought to be good, particularly for those who are working or have other commitments. Websites and information that people can use without having to speak to professionals in the early stages of mental illness are also very helpful. Online therapies and apps had been used by members of the mental health focus group and they found these to be useful for low level support. For some, it was important to continue to have paper-based information, as well as online options.

What could be better?

- + A more holistic and joined-up approach among health professionals. Instead of each professional just doing their bit, some communication and overall management is felt to be better when facing complex needs. Links between services are seen to be problematic and improved communication should be a priority. Others want an even wider approach, with joined-up services between all support services - health, social care and the voluntary sector - to meet people's needs. Instead of each professional working in isolation, better communication and overall management is needed when facing complex needs.
- + Greater parity as to what is on offer in different areas. Some people experience difficulties in getting GP appointments, others mentioned the post code lottery - for access to regular blood tests or ear syringing at their local surgery, IVF treatment, NHS dentists and mental health services.
- + Better mental health services. There are calls for a wide range of improvements: more specialists; continuity of professionals especially in the early stages to build up trust; involvement for carers in the patient journey; lowering waiting times for appointments with professionals; better communication between professionals; signposting to support groups and networks (including holding evening events); and better mental health training for GPs.

Cancer health and care services

Cancer was one of the specific conditions agreed as a local objective, focusing on the three themes of: prevention, management – diagnosis and treatment; and aftercare and support. Of the 63 people from Central Bedfordshire who completed the condition-specific survey, 24 respondents (16 women and 8 men) referred to cancer. This number is relatively small, which only allows for limited statistical analysis, so this section relies heavily on the comments provided by these respondents and the focus group, attended by 5 women and 6 men aged around 40 to mid 80s.

Prevention and/or early intervention

Preventative health care screening is valued by all members of the focus group. They felt that promotion campaigns were effective, and all were able to name awareness campaigns. They wanted campaigns not just to focus on screening, but provide other information, such as increases in survival and new treatments. Those with recent experience reported that the two-week pathway had been adhered to. Participants wanted the NHS to invest in less invasive screening, which they felt could increase uptake, and they did not want screening restricted by age. They also called for relevant training for all healthcare professionals.

Overall respondents to the survey had had a relatively positive experience in accessing help and support. Seventeen respondents (71%) said that their experience of getting help was positive or very positive. Sixteen respondents (70%) described the time they had to wait for their initial assessment/ diagnosis as OK, fast or very fast. However, people's experiences varied: some said that the initial appointment took too long while, for others, appointments came through quickly.



Assessment, diagnosis and treatment

After diagnosis, focus group participants were generally appreciative of their treatment and care: they mentioned the compassion and understanding from the staff they came into contact with and the efficient process following diagnosis. Of the 21 survey respondents who were referred to a specialist, just three (14%) said the time they had to wait between their initial appointment and seeing the specialist was slow or very slow.

Members of the focus group were complimentary about the compassion and understanding from nursing staff and the support from local and national voluntary schemes and organisations, such as the local Good Neighbour Scheme and Macmillan. They also appreciated being given options and time to make their choices. However, they felt improved communication was needed throughout the cancer journey, as well as more culturally appropriate care and support. They also wanted better co-ordination of treatment and support, and a more holistic approach that takes into account physical and mental health, as well as considering carers. Some were troubled by the high cost of hospital car parking charges and felt information on concessions should be more widely publicised; others were concerned about the availability of accessible and affordable transport for those over 75 years.

The provision of ongoing care and support

Members of the focus group were generally positive about post-cancer support. They gave examples of good organisations such as Garden House Hospice, Good Neighbour Scheme and Macmillan. They valued the opportunity to have choice, particularly if they could use services that were local. Some people wanted to see an improvement in support for carers and families and others wanted more information, including what to expect after treatment.

“Although I got support from the McMillan Unit at the L&D, I would have appreciated being told about support groups or maybe other community groups that I could have attended to get the support needed at the time.”

“The compassion and understanding shown by all nurses involved in my treatment was really good.”

“Help me make my own decisions.”

Mental health services

The second specific condition agreed as a local objective was mental health, again focusing on the three themes of: prevention, management - diagnosis and treatment; and aftercare and support. Just 8 of the 64 people from Central Bedfordshire who completed the condition-specific survey specified a mental health condition. This number is too small for any detailed statistical analysis, so comments provided by these respondents and the Central Bedfordshire focus group on mental health, which was attended by 17 people of a wide age range (mid 20s to mid 80s), have been used.

Prevention and/or early intervention

Some members of the focus group have good experiences of calling helplines and 111 for support, using websites to find information without needing to speak to professionals in the early stages and being seen quickly when at risk. Focus group participants feel that there should be dedicated mental health professionals at GP surgeries and that GPs required more training on mental health. They also want continuity of professionals in early conversations to build up trust and better support for people with multiple needs. They stressed the importance of continuing to fight for social inclusion and reduce the stigma attached to mental ill health. Respondents to the survey complained about unsupportive GPs and long waiting times to see mental health practitioners.

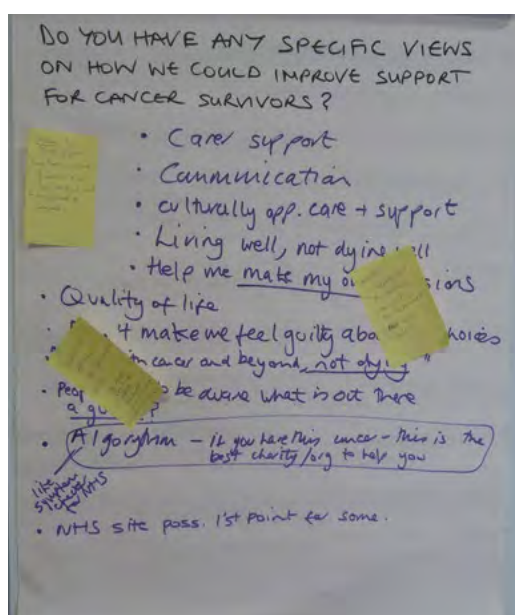


Assessment, diagnosis and treatment

Being offered therapy, particularly counselling, is highly valued by members of the focus group. They have positive experiences of using text as reminders (such as NHS no reply texts for appointments), and online therapies and apps have been used by some members of the group, which they find useful for low level support. They feel that there are some good staff in all services, but others were not always considerate. Nearly all those attending complained that waiting times for appointments with all professionals (GPs, mental health community care, general hospital services, counselling, talking therapies) were too long. They want improved communication between different departments, which they suggested could be brought about by digitalisation. They thought that therapies that work in conjunction with each other and are delivered together would provide more comprehensive treatment, and they wanted parity in mental health service provision across geographical areas. Some respondents to the survey also mentioned long waiting times and the lack of continuity in care.

"The only support I had was the crisis team, who came and sat and watched TV with me, or going to A&E who told me I had to see my GP. The community psychiatrist is a different person nearly every time I go. There is no continuity of care and I have to re-cap my history at every appointment. They all have their own ideas of what medication to try, which is continually confusing me and not helping me get any better."

"Currently undergoing CBT which has provided a bit of support, but not resolved any of my mental health issues. The waiting time for this treatment was approximately 3 years."

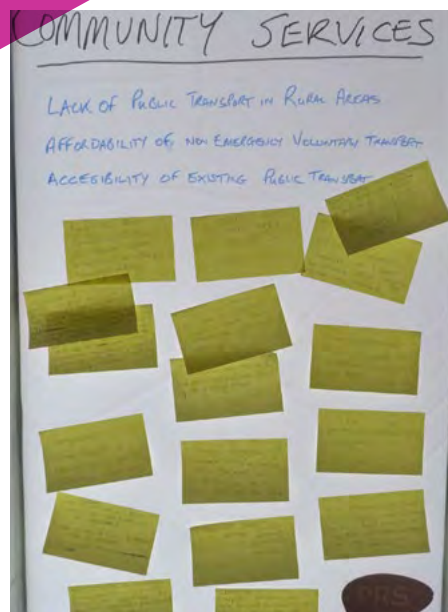
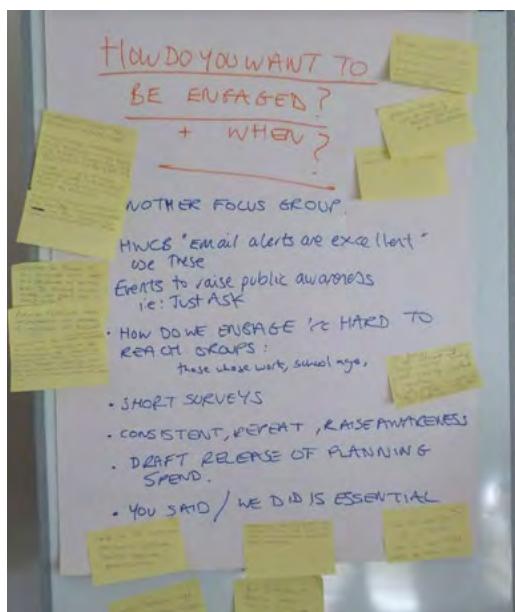


The provision of ongoing care and support

Members of the focus group are positive about support from family, friends and the acquaintances they have made on their mental health journey, as well as groups such as Mind2Gether that are highly valued. Courses such as IMPACT - run By Path2Recovery - are accessed by some members of the group, who think them beneficial. People also feel there is a need for better signposting to networks and groups. It is well known that staff turnover can be high in mental health services - participants feel that a handover, where possible, would make the transition easier for people. They also want more help to understand the progression of their care.

"Mental health help and support is very limited in Central Bedfordshire and it's even more limited if you live in Leighton Buzzard. There is only one service running via MIND, the rest is down to the GP. As someone who suffers from mental health issues there needs to be more mental health services in the town of Leighton Buzzard. I'm fed up of having to keep going to my GP who doesn't help me one bit with my mental illness. Something has got to be done about this and the sooner the better."

Survey respondent

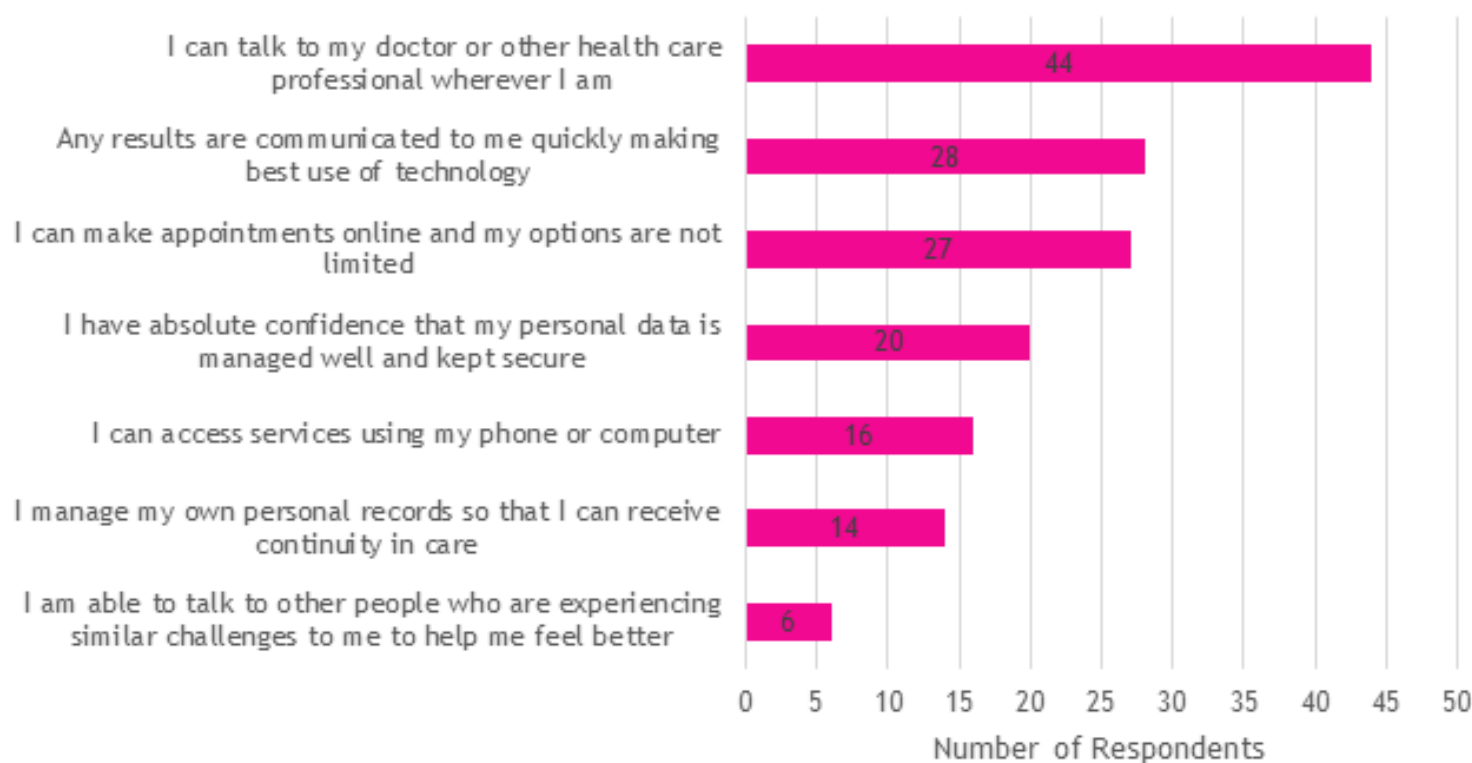


Engaging people in health service delivery

What people expect during their treatment journey

'I can talk to my doctor or other health care professional wherever I am' was rated as the most important of the seven statements shown in the chart below when interacting with the NHS by 28% of people who answered the question, followed by 'any results are communicated to me quickly making the best use of technology' (18%) and 'I can make appointments online and my options are not limited' (17%).

What is most important when interacting with the NHS?



When people were asked to rate the importance of each statement shown in the chart (on a five-point scale ranging from 'very important' to 'not important at all'), the proportion of people who rated them as important or very important ranged from 89% for 'any results are communicated to me quickly making best use of technology' to 63% for 'I am able to talk to other people who are experiencing similar challenges to me to help me feel better'.

What works well?

- + Preventative screening and public awareness schemes
- + Compassion and understanding from NHS staff
- + Self-help information, including apps for mental health services

What could be better?

- + A more holistic joined-up approach among health professionals, with improved communication between departments
- + Shorter waiting times for treatment and better availability of GP appointments
- + Better signposting to information, networks and support groups

“It would be good to have knowledge available or where you can source this information either online or/and in paper format for those who do not have access to a computer.”

“Better communication - timely interventions, especially with mental health support. When patients are in crisis, they need help immediately. Community Mental Health Teams are not able to respond quickly so the only option is A&E - asking patients with acute MH issues to wait hours for help is not acceptable.”

“Being able to see my GP within days as opposed to weeks.”

What people expect during service change and transformation

Each of the focus groups in Central Bedfordshire asked people about when, and how, they wanted to be engaged about the plan.

When?

- + Engagement should take place at all stages - people felt that information was key to understanding the changes that might affect their care and support.

How?

- + Representatives should join local meetings to engage with local people.
- + Engagement should be done in a range of ways, not just online as this would leave out certain segments of society.
- + Attempt to engage everyone, including those who are hard to reach, those who work and school-age children. Use the media, and voluntary and community groups, to get the message out.
- + Honest engagement should include updates on what is being done, and what isn't, and the reasons for it.
- + Feedback following engagement is important, so people know the information they have provided has made a difference - case studies are important, not just statistics.
- + Use a more creative approach - offer incentives, token box idea (similar to charity model in supermarkets: shoppers given a token at checkout but use it to, for example, pick the most important area for NHS improvement).
- + Feedback should be given to impartial, independent bodies.

How the NHS can make care better for people with Down syndrome – Nicola's story

Two babies with Down syndrome are born every day in the UK, according to charity Down Syndrome Extra 21.

What does having a child with a learning disability mean for a parent? What support is available to help the child and their families live happy, healthy lives?

Nicola, whose teenage son has Down syndrome, shares her views about what would make health services better for people with learning disabilities.

Better training

Caring for a child with Down syndrome has meant frequent visits to local health services for Nicola. She told us she would like to see more training for staff in providing suitable environments for people with learning disabilities.

“Life with a disabled child is certainly different - with frequent need to call on the health service. Mainly I want professionals to see the child first and not the Down syndrome. I want to be treated with respect and listened to when I know how I want my child treated.”

My child has had some wonderful care from dedicated caring staff, but there have been gaps in provision. Services such as speech therapy are stretched very thinly. I would like to see more training for staff in recognising and working with people with learning disabilities and providing suitable environments for care.”

Easier access to support

Finding information and support can be a worrying and stressful process. Accessing services in rural communities can be even more difficult. Nicola says it is vital people do not have to struggle to get to the help they need.



‘Mainly I want professionals to see the child first and not the Down syndrome.’
Nicola

“Central Bedfordshire is a very rural area with limited public transport, so it is essential that delivery is spread across the area and it’s not immediately assumed that certain care can only be delivered in a hospital.”

Help people help the NHS

It is not always necessary to see a doctor. With the NHS under increasing pressure, Nicola says it is vital that people understand which services they should use and when.

“I feel we should train people to use the NHS wisely and only use urgent services when absolutely necessary, but equally not to ignore symptoms that need looking at.”

Wider use of pharmacies could reduce pressure on GPs, as well as increased Skype consultations. We must be careful not to rush to a total move into online services as many do not have access to the internet or do not want to use it, but the option to do so would be good.”

Luton

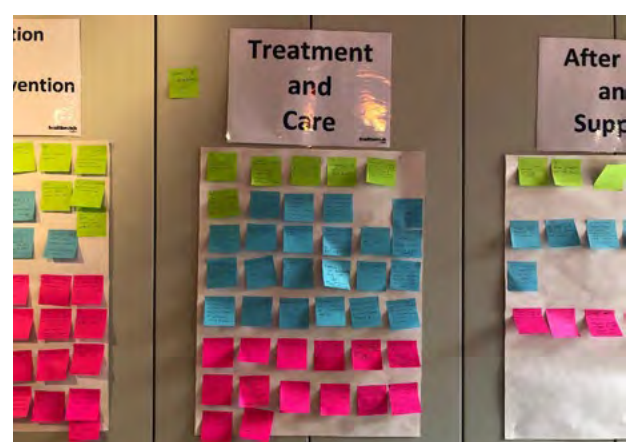
Background

Luton is a densely populated and multicultural town. The proportion of people from an ethnic minority group (40%) is three times the England average. It has a much younger population age structure than England overall, with 26% aged under 18 and 12% aged 65 and over. The health of people in Luton is generally poorer than the England average. Luton is one of the 20% most deprived districts/unitary authorities in England and 19% of children live in low income families. Life expectancy for both men and women is below England overall⁵.

Summary of findings

What matters most to people in Luton?

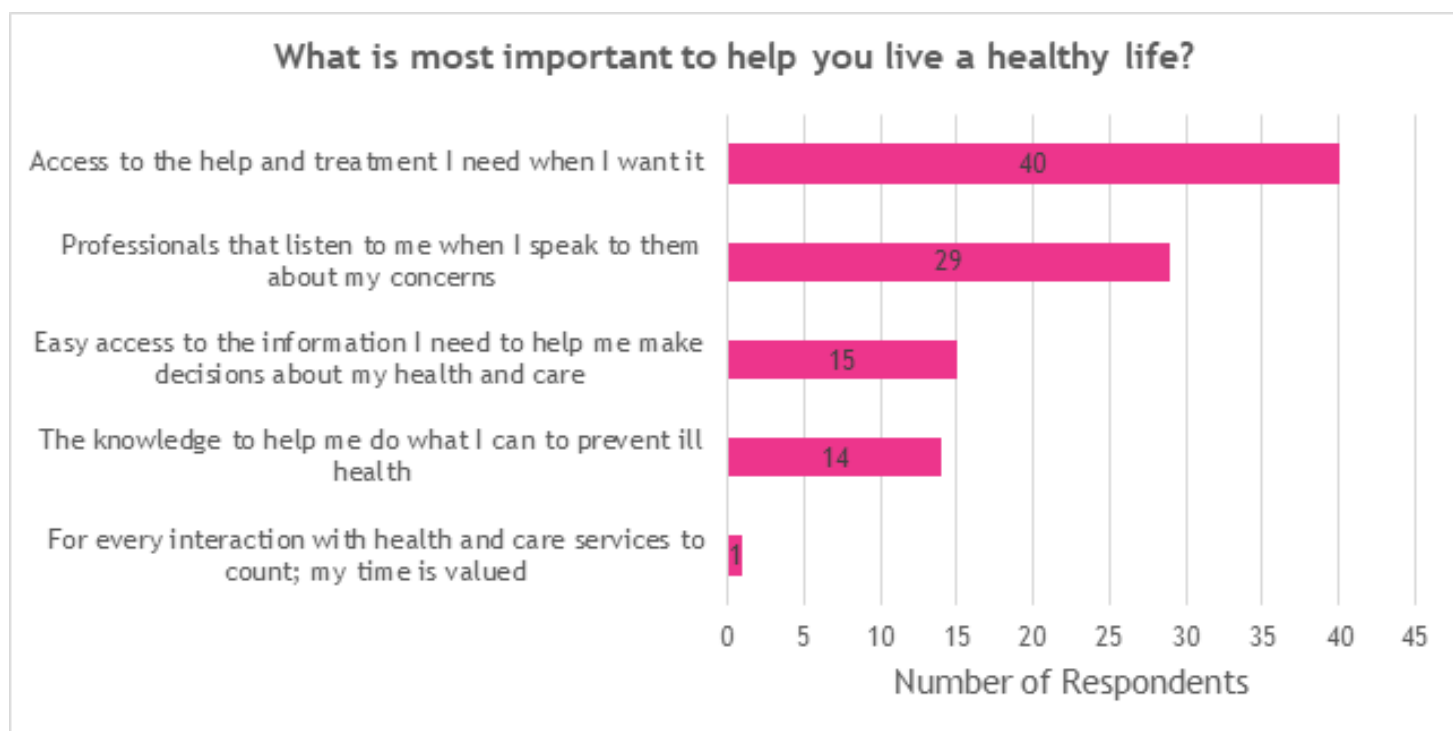
Healthy life



Overall, two-fifths (40%) of people in Luton said that ‘access to the help and treatment I need when I want it’ was the most important of the five statements shown in the chart in helping them to live a healthy life. The second most frequently chosen statement was ‘professionals that listen to me when I speak to them about my concerns’ (29%). There was some variation by ethnic group. For people from Asian ethnic groups (Asian British, Indian, Pakistani, Bangladeshi), ‘easy access to the information I need to help me make decisions about my health and care’ was the second most important option - 5 of the 15 respondents (33%) chose this, which was three times the proportion for people from the White British group. People with more than one long-term health condition and those with a disability viewed ‘professionals that listen to me when I speak to them about my concerns’ as the most important option (50% and 55% respectively).

⁵Public Health England, Local Authority Health Profiles, Luton, available at: https://fingertips.phe.org.uk/profile/health-profiles/area-search-results/E06000032?place_name=Luton&search_type=parent-area

Suggestions for what more could be done to help people live a healthy life centred around improved access to professionals and services, and the need for better communication to create a greater awareness of those services that do exist. Others felt there was a need for access to groups or affordable fitness programmes, particularly locally.



“Dentistry to become free so adults aren’t put off getting any appointments made.”

“Greater access to preventative screening.”

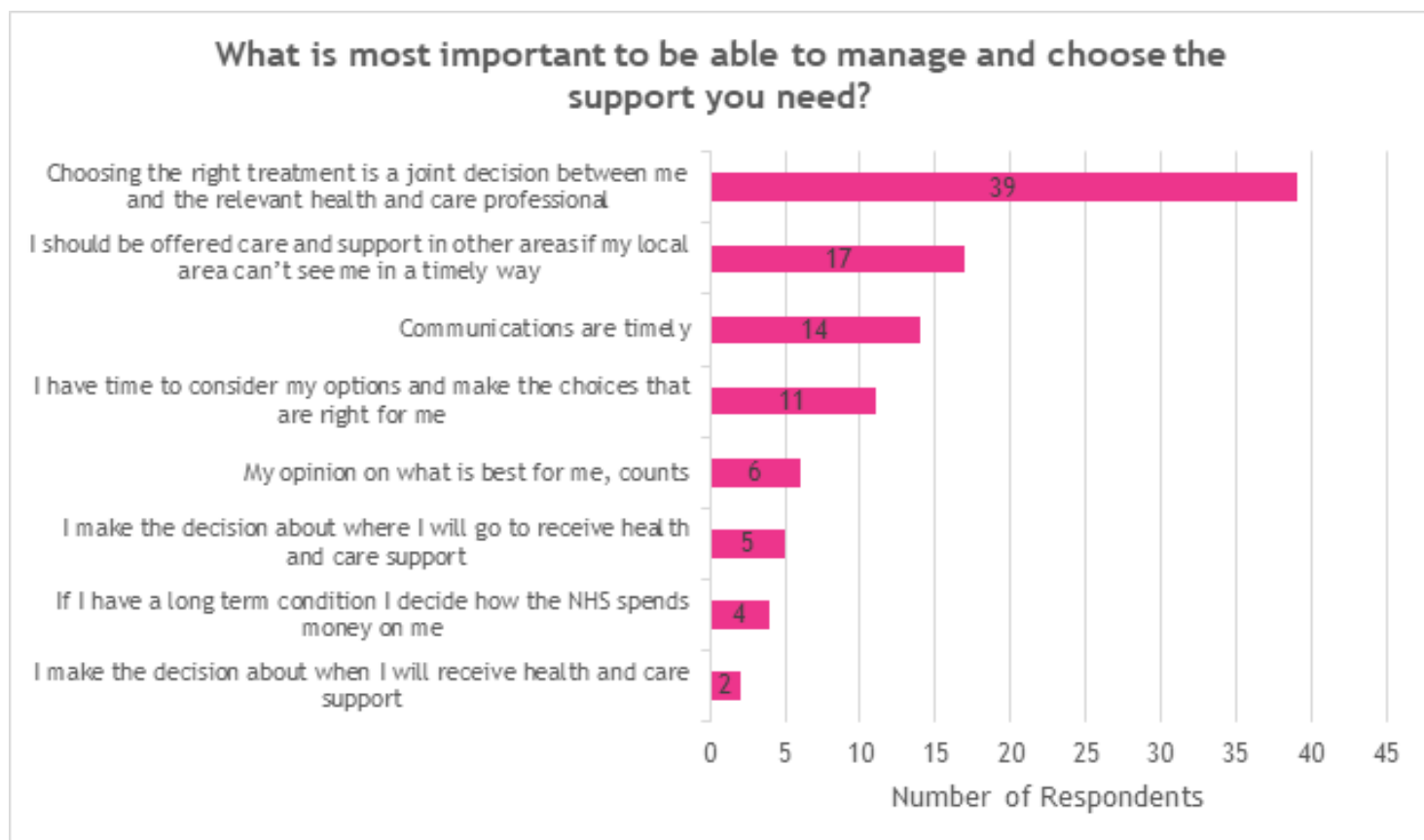
“Ways to get in touch with others who might do things like go on walks with me.”

“Easier access to affordable fitness programmes and activities available more locally, not everyone has access to a car or can afford multiple bus/taxi charges.”

Manage and choose support

‘Choosing the right treatment is a joint decision between me and the relevant health and care professional’ was seen as the most important statement for people in Luton in being able to manage and choose the support they needed - four in ten people chose this out of the eight options shown in the chart below.

Many people suggested that solving the issue of being unable to book an appointment with a GP in good time would help them to manage their health and care, and working people particularly need more flexible access to their GP. Some people, mainly the older generation, do not necessarily have access to technology and want to be able to access services using their phone.



“I wish I could talk to my doctor. I wish I could make appointments.”

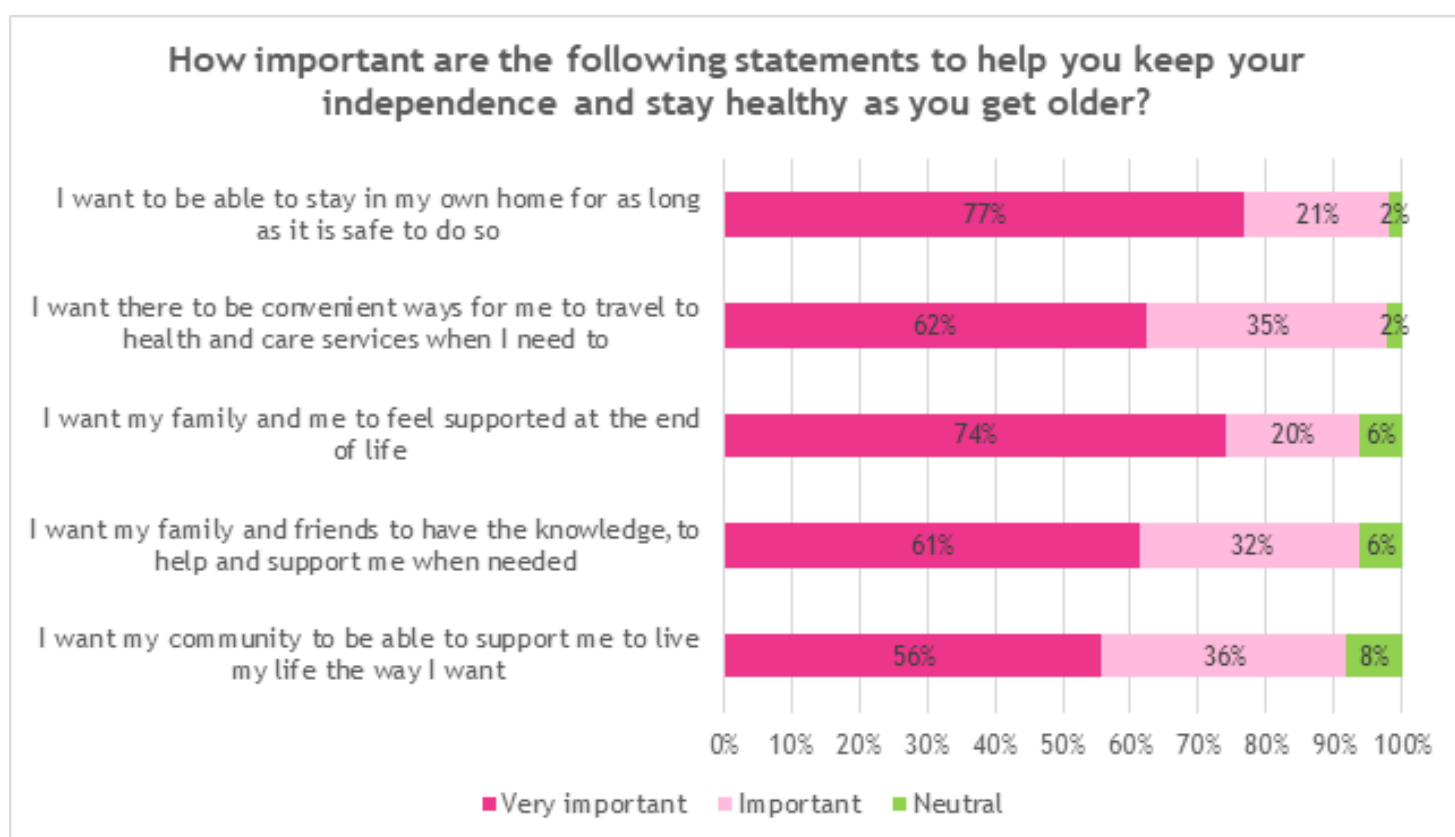
“It is important that health professionals remember that not everyone uses IT/computers and mobile phones.”

“We have a large ethnic minority population in Luton, the largest of which is South Asian with its particular culture and languages. The socio-cultural and linguistic barriers are even more prevalent in the older people’s groups, requiring support. It helps to remember that online, digital services are not widely used in the elderly population in general and with the ethnic minority groups it’s even lower. So, the communications and the booking appointments systems need to factor that in.”



Independence and staying healthy with ageing

People in Luton attach a high importance to being able to stay in their own homes for as long as possible when they get older. Around three-quarters (77%) rated 'I want to be able to stay in my own home as long as it is safe to do so' as very important, and a further 21% said it was important (on a five-point scale ranging from 'very important' to 'not important at all'). When they were also asked what they thought was the most important of the five statements, this statement was chosen by 36% of respondents. The proportion increased with age: 33% of 18-54 year olds said it was the most important of the statements, rising to 55% of those aged 65 and over.



When people were asked for suggestions for what would help them to retain their independence, a common theme was more home care to enable them to stay in their homes. Several responses were related to their family and friends - giving them support too and involving them in conversations.

“Social care support to be available so people can be safely discharged from hospital unlike the present situation where there is a waiting list for getting the social care.”

“Giving my family the support they need also - not just looking at patient but all the needs.”

“Very important to train immediate family members with care and support. Sometimes we need information to be provided about services that we don’t think exists.”



What did they tell Healthwatch?

Local engagement took place through three focus groups in Luton, attended by 46 people in total and covering a wide age range from mid 20s to mid 80s. The members of the groups were generally well engaged, with some more vocal than others. The mental health group was highly emotional throughout. Many useful suggestions were also received through the free format questions on the survey.

What works well?

- + Once people are in the system, then treatment works well. In particular, peoples' experiences with cancer are that once they were through to a specialist, the treatment and support was exceptional and timely.
- + People are on the whole are positive about the staff that they come into contact with - consultants, the health facilitation team at Luton & Dunstable hospital, care co-ordinators, Active Luton staff, MIND and, particularly, Macmillan nurses.
- + Initiatives to keep people healthy are seen as important and helpful. This includes annual health checks, activity schemes for people with long-term conditions and Active Luton subsidies for aftercare exercise.



What could be better?

- + Getting access to services remains a high priority for everyone. People want, and need, support 24/7 and not just during working hours - for all services, with more support needed in early intervention and prevention. They also require social care support, so they can continue to live in their own homes. Being unable to book an appointment with a GP in good time was a recurring theme in the survey and focus groups. Working people struggle to access care and support and need more flexibility in the hours it is available, with this lack of early intervention possibly leading to A&E attendance or crisis.
- + Awareness of services is lacking: during the focus groups people said that they did not know that some services existed (for example, extended hours, 111, primary Care Link workers). There needs to be better communication with the public - for many this can be done electronically, but some, particularly the elderly, do not have access to technology.
- + People wanted more choice on where to receive their care. They are willing to travel for specialist care and support for health conditions like cancer, although the cost of transport can be a concern. For mental health care, people thought it was important that it should be closer to home.

Cancer health and care services

Cancer was one of the specific conditions agreed as a local objective, focusing on the three themes of: prevention; management - diagnosis and treatment; and aftercare and support.

Of the 69 people from Luton who completed the condition-specific survey, 11 respondents referred to cancer. This number is small for detailed statistical analysis, and therefore this section relates to the qualitative information collated by these respondents and the focus group, which was attended by 17 people aged from late 20s to mid 80s.

Prevention and/or early intervention

Focus group participants feel that early intervention is key, but that prevention and early intervention is generally poor and needs more support. This view is supported by the survey where the majority of respondents (10 out of 11) felt that, when they first sought help, the support they received either did not, or only somewhat, met their needs. People told us about the difficulty of getting a GP appointment, and the GP being dismissive and failing to refer. They want correct diagnoses, quick referrals without having to rely on primary care, and better screening.

Assessment, diagnosis and treatment

After diagnosis, people generally felt very positive about their treatment and care. Of the 11 survey respondents, 9 were offered access to further health and care after assessment/diagnosis and 8 of the 11 said that the time they had to wait between initial appointment and seeing the specialist was OK or fast. People praised the supportive staff and good clear communications. However, they want to be able to see specialists closer to home, have more personalised treatments and be given more choice on where they receive support and treatment.

The provision of ongoing care and support

Aftercare is generally thought to be good but the support available needs to be communicated better. Members of the focus group were complimentary about the aftercare provided by Macmillan and the support groups. However, they feel that more support is needed for family, friends and carers - they wanted the family to be involved in the aftercare.

"Once I saw specialist it was all quick and good, but GPs are gatekeepers to referral."

"Once realised what they thought it was things moved fast. Just GP referral holding process up."

"Macmillan support amazing - need more than just hospital support though. Want support for my family and friends."

"Assigned cancer nurse helps."

Mental health services

The second specific condition agreed as a local objective was mental health, again focusing on the three themes of: prevention: management - diagnosis and treatment; and aftercare and support. Fifteen of the 69 people from Luton who completed the condition-specific survey specified a mental health condition. Again, this number is small for detailed statistical analysis, however the comments provided by these respondents, and the Luton focus group on mental health that was attended by 14 people aged from mid 20s to mid 80s, are valuable.

Prevention and/or early intervention

The overall view of the focus group was that more support was needed in prevention and early intervention. They feel that early intervention is important, as well as better communication to promote services before people get to crisis. They mentioned long waiting times from referral to appointments. Five of the 15 respondents to the survey said that the time they had to wait to receive their initial assessment was slow or very slow. Comments from them included the need for shorter wait times and more sessions.

Assessment, diagnosis and treatment

The focus group expressed the view that treatment and diagnosis also needs improving. There are some good experiences, with people mentioning having a care co-ordinator, good treatment and counsellors, and that the cluster support was good. Suggestions included: managing relationships more robustly through transitions; having access to support nearer people's homes; and not just prescribing tablets. There were some positive comments from the survey respondents - for example, being offered one to one counselling, face to face CBT rather than just phone support - but mostly there were mentions of long wait times, group rather than one to one sessions, and inadequate support. Respondents suggested that more counsellors were needed to cut waiting times and more options need to be available - for example some people are uncomfortable with counselling. Another suggestion is to have online assessments on a regular basis, with easily accessible help if required, rather than having to reapply for support.

The provision of ongoing care and support

The experience of the people at the focus group suggests that aftercare needs more investment. MIND is seen to provide good ongoing support and the specialist knowledge is good. Suggestions included joint planning of services, improving the transition from being an inpatient to moving out into the community, information on counselling options being communicated better, and allowing self-referral or referrals from family members. Eleven of the 15 respondents to the survey said that they needed the NHS to supply at least some support to help them stay healthy.

“Manage relationships more robustly through transition.”

“Never offered anything other than pills by my GP.”

“When you have mental health issues and seek assistance, you need it immediately - not in 3 weeks or 6 months. It is difficult to explain to a GP’s receptionist your urgent need.”

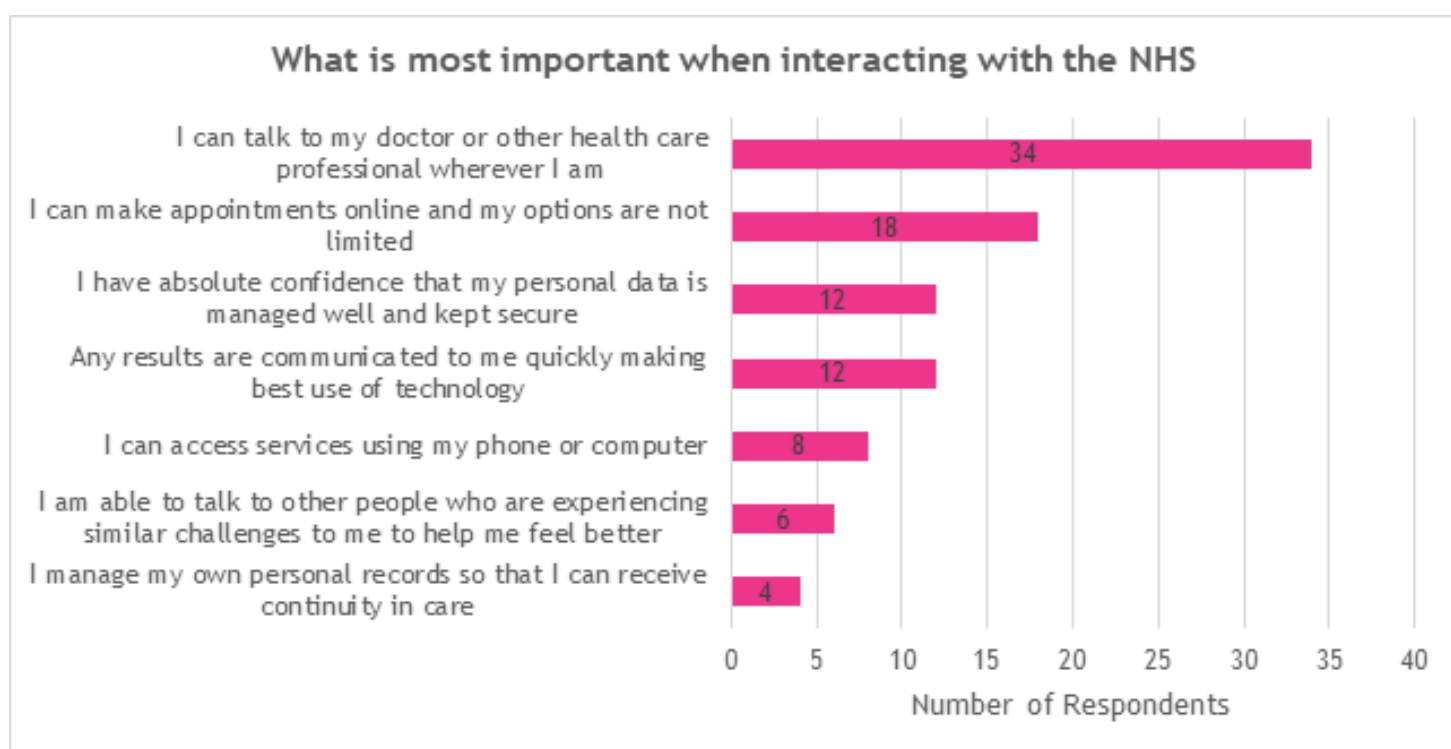
“I would like 1:1 counselling and support in a suitable environment.”



Engaging people in health service delivery

What people expect during their treatment journey

‘I can talk to my doctor or other health care professional wherever I am’ was rated as the most important statement when interacting with the NHS by 36% of people who answered the question, followed by ‘I can make appointments online and my options are not limited’ (19%).



However, all of these statements are important to people. People were then asked to rate the importance of each of these statements (on a five-point scale from ‘very important’ to ‘not important at all’) and each of the seven statements was rated important or very important by at least three-quarters of those who responded. This ranged from 93% rating ‘any results are communicated to me quickly making best use of technology’ as important/very important, to 76% for ‘I manage my own personal records so that I can receive continuity in care’.

What works well?

- + Once people see a specialist then care is generally good and timely, as discussed earlier.
- + The staff people come into contact with are knowledgeable, responsive and caring, and good at explaining treatment.
- + Support groups and the work of the voluntary sector (for example, Macmillan) are valued.

What could be better?

- + Being able to get a GP appointment when you need one, at a place convenient to you.
- + The opportunity to discuss options and consequences for care and support, and be listened to.
- + Holistic care, so separate but potentially connected health issues can be understood together.

What people expect during service change and transformation

Each of the focus groups in Luton asked people about when and how they wanted to be engaged about the plan.

When?

- + Answers ranged widely about how often people wanted to be consulted - from constantly to six-monthly.

How?

- + Information should be promoted more widely - for example, through local papers, advertisements and at doctors' surgeries.
- + People also advocated the use of forums, run by external/independent providers.
- + They wanted to give feedback to an independent body, like Healthwatch or trained and accredited people.

How the NHS can make care better for people with Cancer — Andrew's story

"The journey began in the winter of 2017 when I was experiencing pain in my hip bone region, and subsequently went to my local GP for some treatment, which was diagnosed as sciatica. This went on for six months, whereby the same diagnosis was established, but the pain had increased substantially. I then tried acupuncture, physiotherapy and finally a chiropractor, where fortunately they X-ray you prior to any treatment being implemented, which revealed cancer images in the left pelvic bone. The chiropractor booked me in for a private MRI in London, which then revealed the full extent of the cancer in the hip bone and beyond.

I returned to the doctor in question as he was the only one I had seen throughout this ordeal with clear evidence of the extent of the prostate cancer which was so bad the Prostate-specific antigen (PSA) reading was 1275. I was taken to hospital for immediate treatment, and at one point they were contemplating operating on the pelvic bone immediately as it was going to snap, but thankfully this wasn't the case, but it had also attacked the spine on the course of its journey.

Hormone therapy treatment in conjunction with chemotherapy reduced the PSA to below normal levels of between 2-4 after only 4 sessions which was very positive news, but we have to remember it is incurable once it has entered the bone region, so we had become reliant on the hormone treatment for life and it can contain the cancer from breaking out.

Sadly, in April this year, the PSA rose again to 153 and had spread into my groin and hip areas and radiotherapy has been applied in order to hopefully destroy the cancerous cells in these joints.

So how do you sum up this life-threatening disease in order for this not to happen to anybody else?

Firstly, stories like mine have to be shared to the general public in the hope it will shock people in getting tested, and more importantly explain what



'Doctors and surgeries are under increasing pressure and oversights can be attributed to any type of medical problem'
Andrew

PSA stands for because a large majority of men like myself haven't got a clue what this represented at the time.

Secondly, it is vital to insist on a PSA test at your doctors despite the possible questions as to why you feel you need one, and more importantly do not take the doctors word as gospel. I should have challenged his judgment being in so much pain for so long, and it took my own initiatives in getting myself diagnosed and extending my life.

Doctors and surgeries are under increasing pressure and oversights can be attributed to any type of medical problem, but if the knowledge is shared in the general domain then there is a better chance that men will take this very seriously and insist on being checked for their own piece of mind.

My life is a day to day encounter, and positivity is a crucial element of this giving me and my family every opportunity in enjoying the time we have left together, but please, please, please when you read this, the natural thing to say to yourself is, this doesn't apply to me I'm fine, it only happens to others - WRONG, cancer has no loyalties no discriminations and no safety barriers unless you impose them."

Milton Keynes

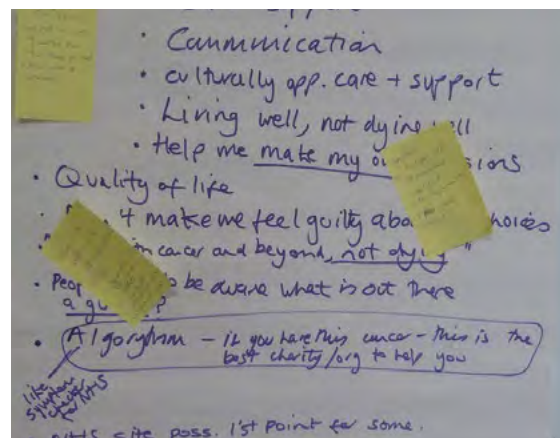
Background

Milton Keynes was designated as a new town in 1967 with the aim to become a 'city' in scale. It has the UK's fastest growing economy, yet it has nine areas that are in the 10% most deprived in England, as well as 12 in the 10% most affluent⁶. Milton Keynes has a much younger population age structure than England overall, with 25% aged under 18 and 13% aged 65 and over. The proportion of people from an ethnic minority group (17%) is above the England average (14%). The proportion of children living in low income families (15%) is slightly below, and life expectancy for men and women is similar, to England overall⁷.

Summary of findings

What matters most to people in Milton Keynes?

Healthy life



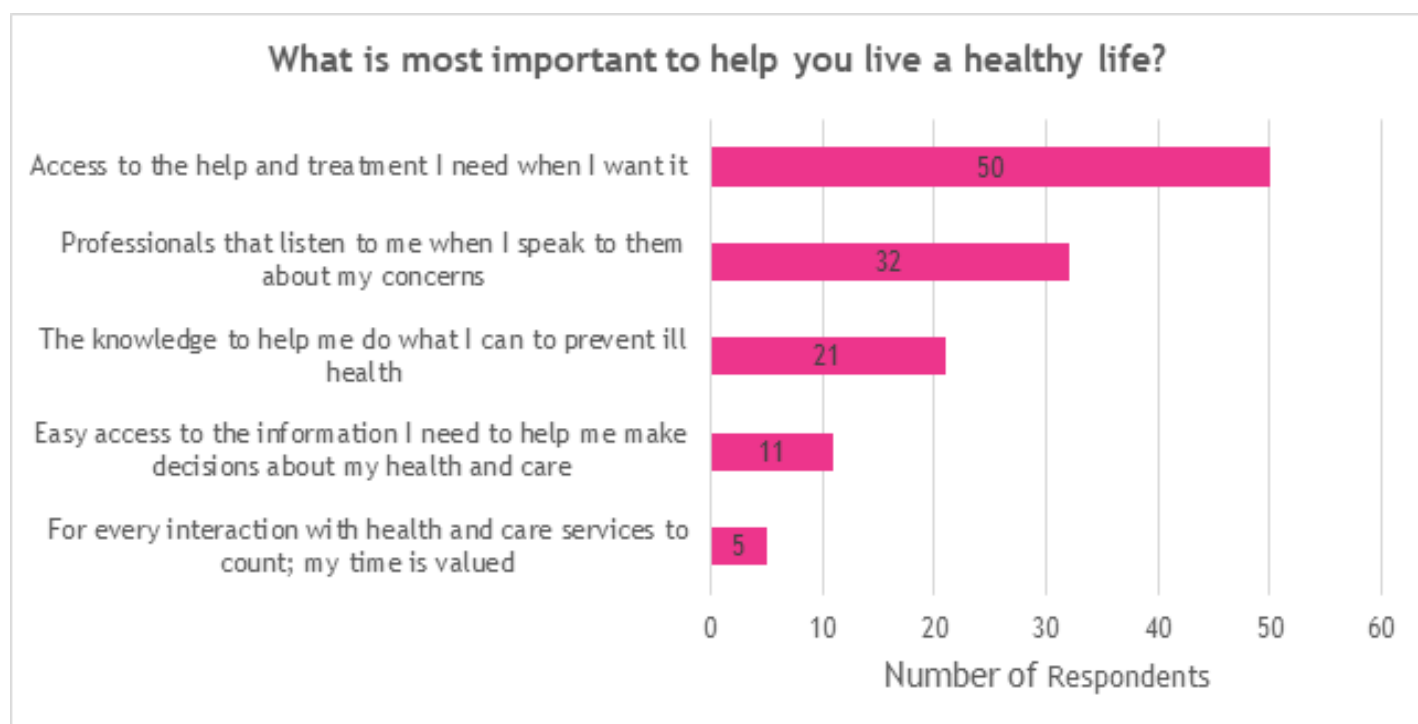
People in Milton Keynes were most likely to say that 'access to the help and treatment I need when I want it' is the most important of the five statements shown in the chart below in helping them to live a healthy life, with 42% choosing this option. Men were more likely than women choose this statement - 67% of men did so compared with 36% of women - but it was still the most frequently chosen option for both genders. People with a disability were equally as likely to choose 'professionals that listen to me when I speak to them about my concerns' as the most important (around 40% for each of these two statements). However, they are all important to people. When people were then asked to rate the importance of each of these statements (on a five-point scale from 'very important' to 'not important at all'), each one was rated important or very important by well over 90% of people.

⁶Milton Keynes Council, 2016/17 JSNA Deprivation, available at:

<https://www.milton-keynes.gov.uk/social-care-and-health/2016-2017-joint-strategic-needs-assessment/draft-16-17-jsna-place/2016-17-jsna-deprivation>

⁷Public Health England, Local Authority Health Profiles, Milton Keynes, available at:

https://fingertips.phe.org.uk/profile/health-profiles/area-search-results/E06000042?place_name=Milton%20Keynes&search_type=parent-area



Suggestions from survey respondents for what would help people live a healthy life centred around better and quicker access to professionals and services, the need to encourage people to do more exercise through subsidised classes and better access to, and information on, healthier food and diets.

“Better access and understanding how to keep healthy. NHS is very focused on fixing a medical condition and not looking at how to keep healthy whilst living with a condition.”

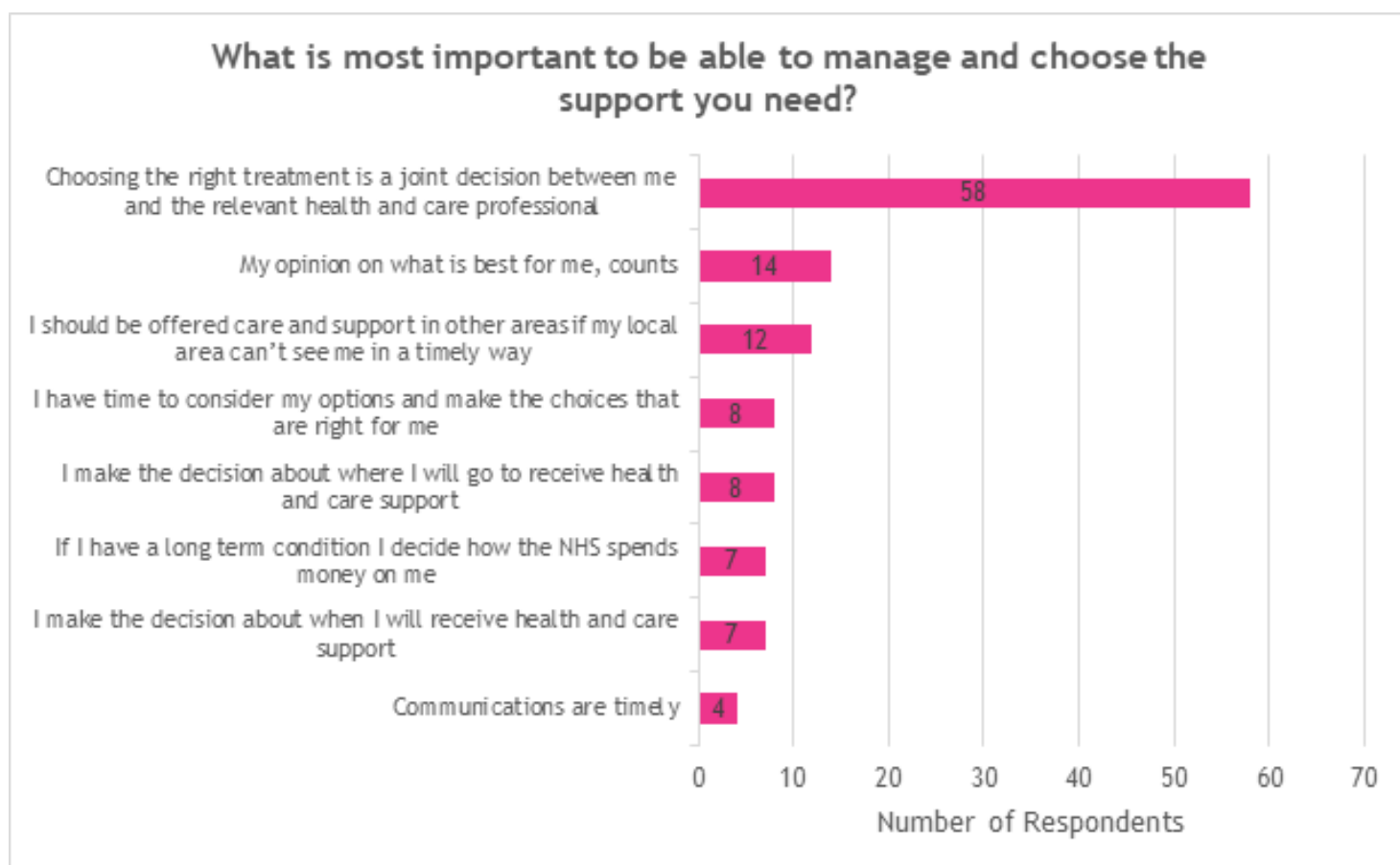
“A nominated GP, able to provide continuity with appropriate referrals, who maintains personal interaction with me.”

“Healthcare programmes for fitness and healthy cooking etc. Teach individuals how to incorporate healthy living into their lifestyles.”

Manage and choose support

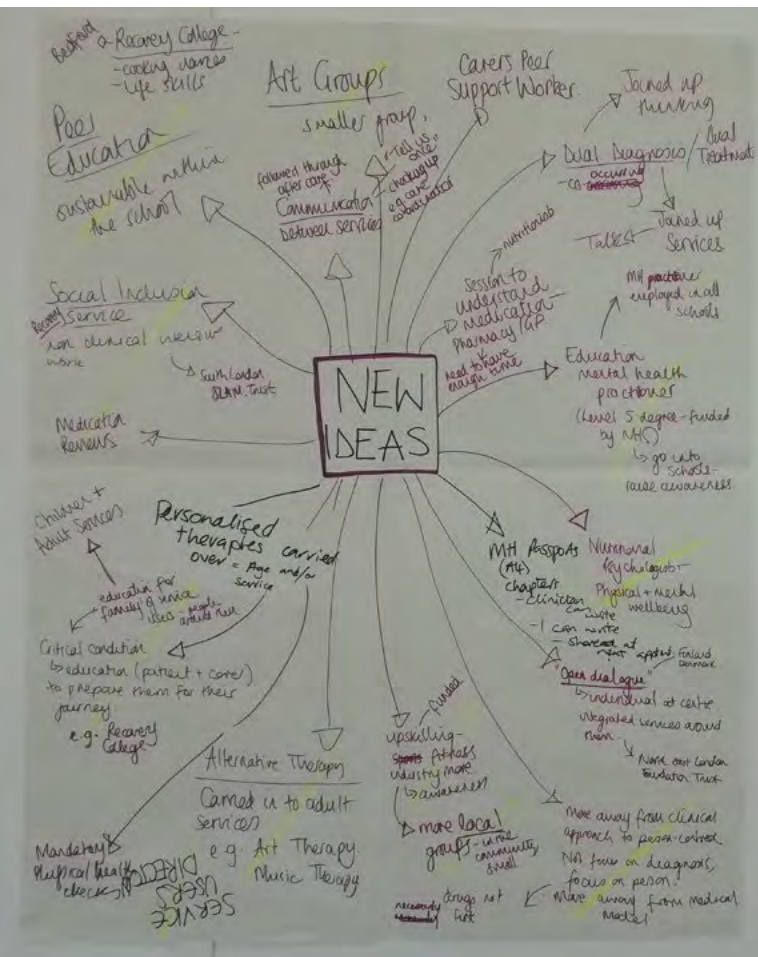
‘Choosing the right treatment is a joint decision between me and the relevant health and care professional’ was seen as by far the most important statement for people in Milton Keynes in being able to manage and choose the support they needed. Almost half (49%) of respondents chose this out of the eight options shown in the chart below.

Common suggestions from focus group participants included: improving access to services such as availability of GP appointments and more local provision of services. Some members of the focus group like the online services that can be used to book appointments, order prescriptions and access their own records and efficiency, but noted that this can put those that do not have access to technology at a disadvantage. Nevertheless, more effective use of IT for communication was one of their suggestions. Survey responses echoed the call for easier and quicker access to services, particularly GPs. Technology also again featured in responses - some expressed concern on the overreliance on technology and that it could put the elderly in particular at a disadvantage; others thought it was useful. Survey respondents also highlighted a need for better access to advice, possibly through drop-in centres.



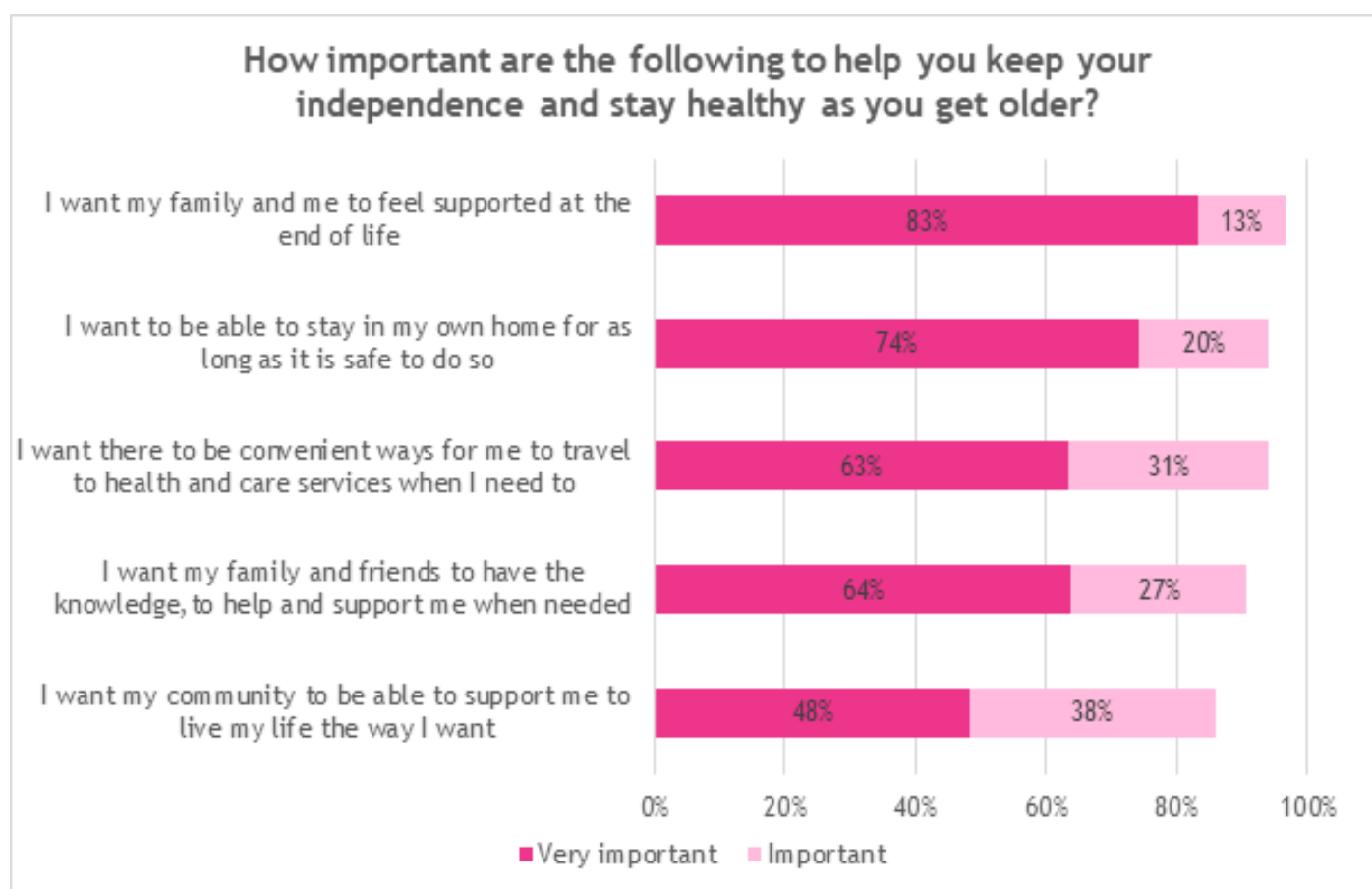
“The personal touch - not all results should be communicated by technology, some need in person explanation & reassurance.”

“Help me to understand in depth what everything means.”



Independence and staying healthy with ageing

People in Milton Keynes attach a high importance to being able to stay in their own homes for as long as possible when they get older. Overall this was deemed the most important of the five statements: 43% chose this option compared with around 13%-16% for each of the other options. People were then asked to rate the importance of each of these statements (on a five-point scale from 'very important' to 'not important at all'). They thought that all the options were important, with 'I want my family and me to feel supported at the end of life' having the highest proportion (97%) of respondents saying it was important or very important (see chart below).



When people were asked for suggestions about what would help them to retain their independence, a common theme was more home care and practical support (such as chairlifts or help with gardening or housework) to enable them to stay in their homes. Other responses included support and advice for family and friends, and access to forms of activity.

“A network of close friends and family backed by a well-resourced and staffed community health service.”

“Exercise in one form or another is vital to health as you get older, so it is essential that convenient services are available to help and encourage the elderly.”

“Really working on making local communities work to be all inclusive so all ages, classes, ethnic groups, socialise together. This needs a dedicated community centre in each area to act as a focus.”



What did they tell Healthwatch?

Local engagement took place through three focus groups in Milton Keynes, attended by 37 people in total and covering a wide age range from late teens to mid 70s. In addition, useful suggestions were also received through the free format questions on the survey.

What works well?

- + The range and quality of care available once it is accessed, such as the new mental health provision in primary care, community care in some GPs' surgeries, Willen at Home end of life scheme and person-centred care with empathetic staff for inpatients.
- + People value the thorough and efficient process for cancer from diagnosis to treatment and aftercare, as well as the high quality of post-surgical care, good communication and empathy and support from clinical staff.
- + The use of IT for speed and efficiency, such as online booking for appointments, online records and ordering prescriptions online.

What could be better?

- + Access to services needs to improve, particularly availability of appointments at GPs, local provision of services (including drop-ins) and social care (including home care, personalised care and continuity of care).
- + Communication across a range of areas: people wanted better communication between different services/departments, and communication that acknowledges patients' needs (for example, for people with hearing loss or those requiring translators). They also want more information so they can make informed and supported decisions and know what services are available.
- + There is a need for a greater focus on the community with localised services (including specialists), community services and community involvement.



Cancer health and care services

Cancer was one of the specific conditions agreed as a local objective, focusing on the three themes of: prevention; management – diagnosis and treatment; and aftercare and support. Of the 40 people from Milton Keynes who completed the condition-specific survey, just 8 respondents referred to cancer. This number is too small for detailed statistical analysis, so this section relies heavily on the comments provided by these respondents and the focus group, which was attended by 16 people aged from mid 20s to mid 70s.

Prevention and/or early intervention

People at the focus group stressed the importance of regular screening and that more needs to be done to educate people, with more effective prevention campaigns. Of the eight people who responded to the survey, four said that when they first tried to access help the support met their needs. Focus group participants told us that they wanted medical staff to spot signs earlier and more research into earlier diagnosis.

Assessment, diagnosis and treatment

Members of the focus group feel very positive about their treatment and care after diagnosis: they mentioned the empathy and support from the staff they came into contact with and that it was a thorough and efficient process from diagnosis to treatment. Nevertheless, they want improvements in the quality of the service, with less wasted time, more staff, more person-centred care and more awareness of co-occurring illnesses. They also feel that improved communication with ‘ordinary language’ and timely communication is needed, with contact made between appointments if necessary. People also want information about treatment/diagnosis to be told to them compassionately, in person by a consultant, with someone with them if they wanted; they suggested information about emotional support, etc should be offered by a specialist nurse. Some people feel they had been left to read up on the information themselves. They also stressed that with choice, comes pressure, so there needs to be support available at that time.

The provision of ongoing care and support

Focus group participants are generally positive about post-cancer support, including long-term follow up and palliative care. They gave examples of good initiatives such as Hope course, Lymphedema Talk, Look Good Feel Better, and Living with Cancer Conference. They suggested that awareness should be raised of the services that are available, both community and NHS, and that more support is needed for family and friends. People are complimentary about the aftercare provided by Macmillan and the support groups. However, they said more support was needed for family, friends and carers – they feel the family needs to be involved in the aftercare.

“If treatment is further away, accommodation must be provided for family - regional centres where families can stay.”

“The standard of care I have received at MK Hospital has been incredible.”

“There was a lack of one to one communication and of understanding as to how my cancer diagnosis was impacted by, and impacted on, my long-standing disability.”

“My consultant treats me with dignity and respect, putting me at ease entirely. Her whole team are equally committed to providing a high standard of service.”

Cancer experience in Milton Keynes — Jo’s story

During our cancer service focus group, we were stunned when one of our breast cancer survivors told us of her experience of recovery and her introduction to prosthetics. There was an audible gasp from everyone else in the room when Jo told us of the emotional impact of having been through treatment, including a mastectomy, for breast cancer and being given her first prosthetic. Jo was given a ‘flesh coloured’ prosthetic. As a black woman, the NHS Flesh colour is not her flesh colour. She told us:

“the impact that this unforgiving gesture had on my mental health and recovery was catastrophic.”

In the same way that different sizes and shapes are catered to in the temporary range, colour should be of equal importance. Just as not every white woman will match exactly the ‘flesh’ tone that is provided temporarily, not every dark skin tone will match - but it would not be difficult to



‘the impact that this unforgiving gesture had on my mental health and recovery was catastrophic.’

Jo

have an ‘average’ skin tone in both black and white available to women until they can get their customised prosthetic fitted.

Mental health services

The second specific condition agreed as a local objective was mental health, again focusing on the three themes of: prevention, management - diagnosis and treatment, and aftercare and support. Twelve of the 40 people from Milton Keynes who completed the condition-specific survey specified a mental health condition. Again, this number is too small for much detailed statistical analysis, but the comments provided by these respondents and the Milton Keynes focus group on mental health, which was attended by 10 people aged around 18 to mid 60s, are valuable.

Prevention and/or early intervention

Early intervention was highlighted by the focus group, as was the need for better awareness. People gave some examples of good practice - Time to Change Campaigns, peer education, street triage service, Primary Care Plus in surgeries - but on the whole felt awareness needs to be raised in the general population, in the workplace and in schools. One suggestion they made is for all schools to have a qualified mental health practitioner funded by the NHS.

The overall view of the focus group was that more support is needed in prevention and early intervention. They feel that early intervention is important and better communication is needed to promote services before people get to crisis. They mentioned long waiting times from referral to appointments. Seven survey respondents said that the time they had to wait to receive their initial assessment was slow or very slow; no-one said it was fast. Comments from them included the sadness and frustration felt about not being able to access suitable support and the lack of awareness about voluntary sector support.

Assessment, diagnosis and treatment

Member of the focus group gave some examples of specific services that worked well (for example, CAMHS art therapy, Campbell Centre, perinatal mental health support) but that more specific services are required and there needs to be more collaboration between services. They want more training in mental health for GPs, and sessions so they can understand medication and have the opportunity to ask questions. There is also concern about the transition process - between inpatient and outpatient services, which they felt was a step down, and the need for an age overlap between children and young people's mental health services and adults.

Respondents to the survey also told us about lack of support, some useful sessions that were too short, and what they felt was overreliance on drugs and not enough counselling. Seven of the 12 respondents said that after being diagnosed/assessed, they were not offered access to further support.

“At first, getting an appointment to see the GP for a mental health matter was not easy. Finally, the GP I saw was supportive and asked if I wanted to manage my anxiety with medication or alternative therapy, I chose the latter, and this led me to be referred to MIND. However, the consultations and counselling I received were not free or easily accessible. I was on a waiting list and had to pay for each session. Had I chosen medication this would have been instantly available. Therefore, I feel the NHS should invest more in community mental health and make it more accessible to everyone. Our local CCG should also invest a lot more in engaging, encouraging and promoting positive mental health and this does not have to be counselling sessions, but other methods can be used similar to what is available in other countries for free. For example, network groups for the elderly, young people, activities in the park etc. - other than pills by my GP.”

Survey respondent

The provision of ongoing care and support

Members of the focus group are positive about some voluntary and community services (for example, Carers MK, The Mix, Rethink) but they want to see improvements in aftercare. They cited the need for more recovery support in the community (for example, a recovery hub with social drop-ins, or peer support workers) and more crisis provision, such as a crisis house, café or local help line. Other suggestions included: mental health passports contributed to by clinicians and patients; an up-to-date, online service users' directory; and a holistic approach to recovery with alternative therapies, upskilling, fitness and nutritional information. One person suggested a social inclusion service, like the Maudsley Trust. All of the 12 respondents to the survey said that they needed the NHS to supply at least some support to help them stay healthy.

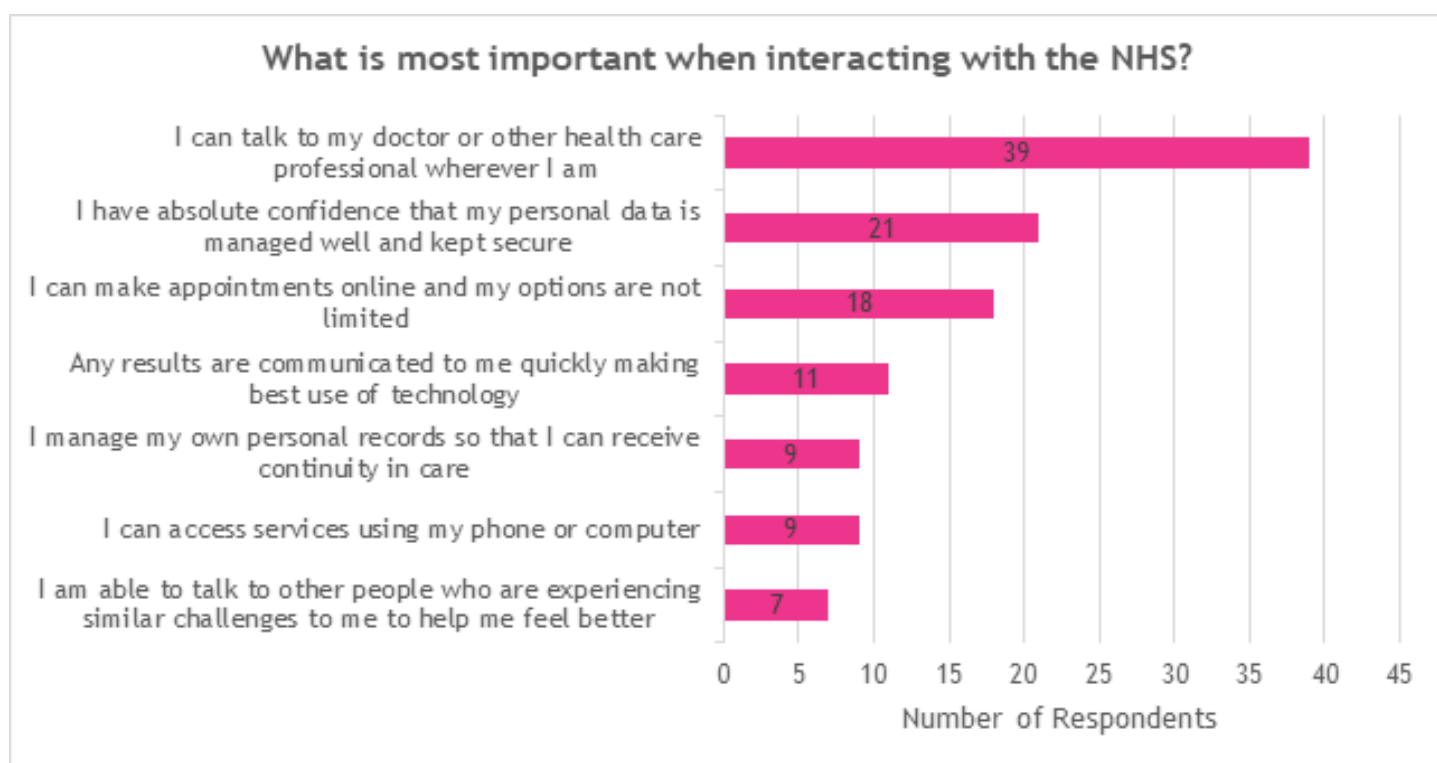
“My son is only alive because he has support at home. Because he is not deemed a suicide risk by the service, we have largely been left to cope alone. This is unacceptable. This is a life that could be lived well and contribute a lot to society but instead he is not being given the professional support he needs to help him to achieve his potential. What a sad state of affairs for young people and a truly desperate one for those without good home support. If anything happens to him there will be regret that help wasn't given when needed and a commitment not to let it happen again. That will be too late for us as it has been elsewhere for others. Are no lessons being learned?”

Survey respondent

Engaging people in health service delivery

What people expect during their treatment journey

'I can talk to my doctor or other health care professional wherever I am' was rated as the most important statement when interacting with the NHS by 34% of people who answered the question, followed by 'I have absolute confidence that my personal data is managed well and kept secure' (18%) and then 'I can make appointments online and my options are not limited' (16%).



However, all of these statements are important to people. When they were then asked to rate the importance of each of these statements (on a five-point scale from 'very important' to 'not important at all'), each statement in the chart was rated important or very important by at least two-thirds of those who responded. This ranged from 95% rating 'any results are communicated to me quickly making best use of technology' as important/very important, to 68% for 'I am able to talk to other people who are experiencing similar challenges to me to help me feel better'.

What works well?

- + The treatment and care of cancer patients, once people have received a diagnosis.
- + The ability for people to access their records, order repeat prescriptions and book appointments electronically.
- + Self-referral for certain services, such as podiatry, physiotherapy.

What could be better?

- + Easier access to health professionals - including direct access to consultants - and health care professionals holding local clinics at surgeries.
- + More advice and drop-in centres.
- + Support groups and access to counselling and complementary therapies.

“Health services seem overloaded probably due to the continuing influx of people into MK, but little investment in health care services. It’s difficult to see a GP, especially the one you are actually registered with and hospital waiting times grow ever longer.”

“Better communication after hospital appointments - I have waited over a month and not heard about my last appointment tests - I have to assume they are all OK.”

“Access to GP appointments, not dependent on impractical or inconvenient 8.00am contact. Recent appointment at Brooklands required a 2 month wait for chosen GP. 8am call said I was number 42 in queue.”

What people expect during service change and transformation

Each of the focus groups in Milton Keynes asked people about when, and how, they wanted to be engaged about the plan.

When?

- + Consultation should take place throughout the process - design, procurement, quality improvement and recruitment (20% of panel should be service users/public/carers, with lived experience as the main priority for the rest of the panel).
- + Annual local reviews.

How?

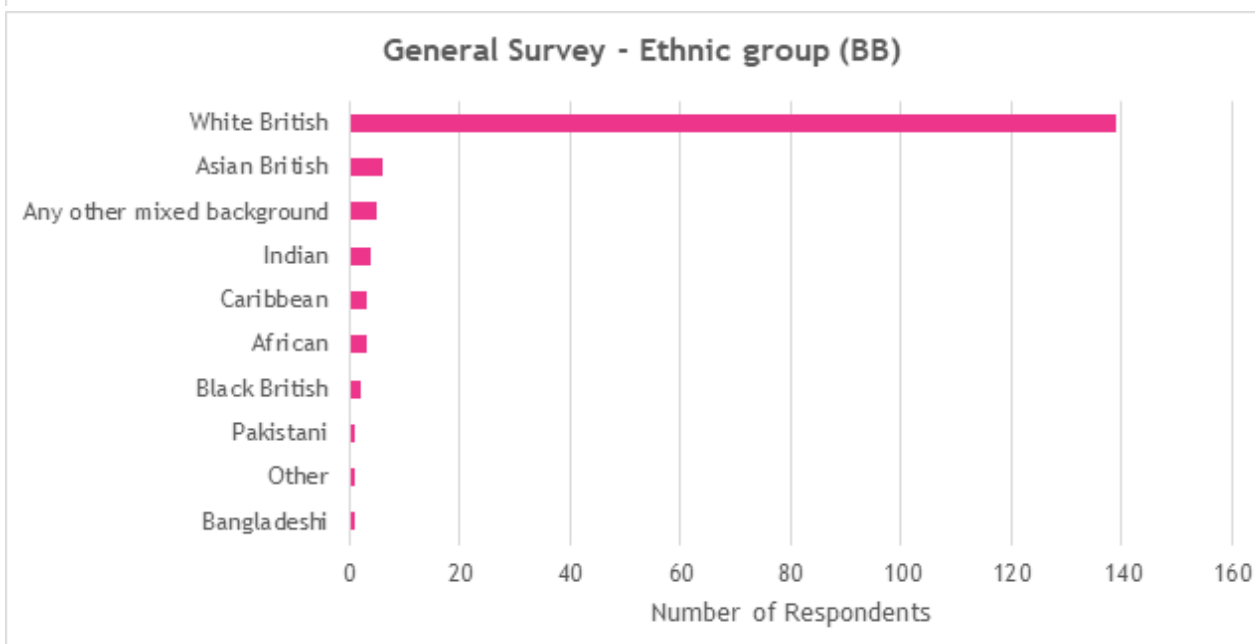
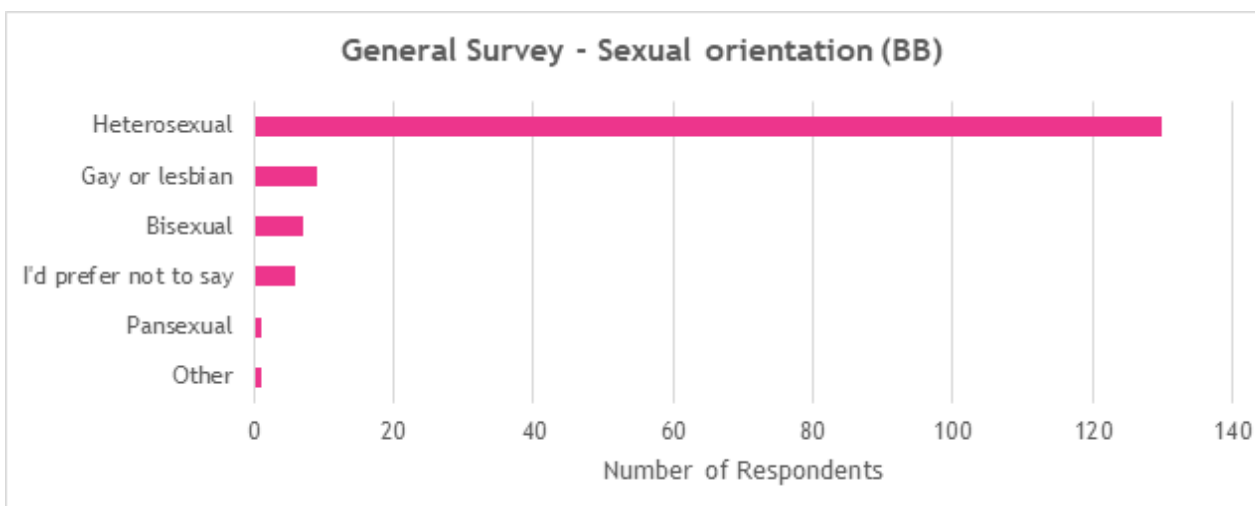
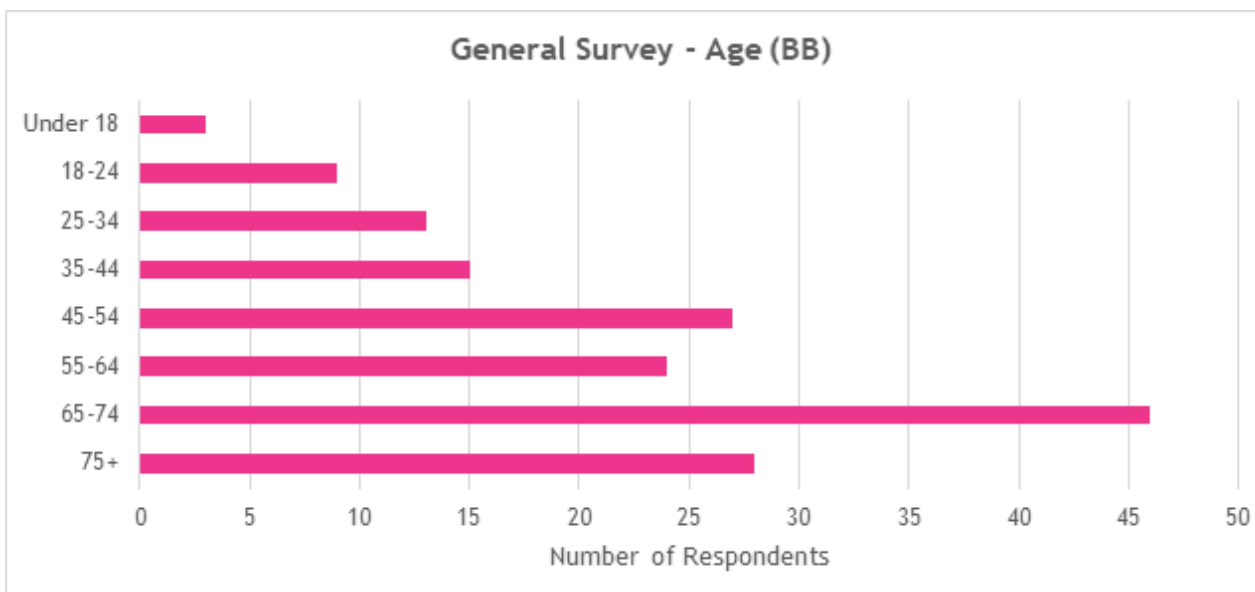
- + Attempts should be made to include a wide range of participants - families, young people (for example through workshops in schools), faith groups, and people who are not using services but should be.
- + Any engagement events should be accessible, for example on public transport routes, have expenses paid, some engagement outside working hours and go to where people are.
- + Feedback should provide the opportunity to give experiences and opinions - not just a tick box.
- + Individuals should have the opportunity to give anonymous feedback on a continuous, regular basis.
- + Make use of groups such as PPGs and national organisations (for example, Macmillan) to draw together people to be involved in the engagement process.
- + Use a more creative approach - offer incentives, token box idea (similar to charity model in supermarkets - shoppers given a token at checkout but use it to, for example, pick the most important area for NHS improvement).
- + Feedback should be given to impartial, independent bodies.



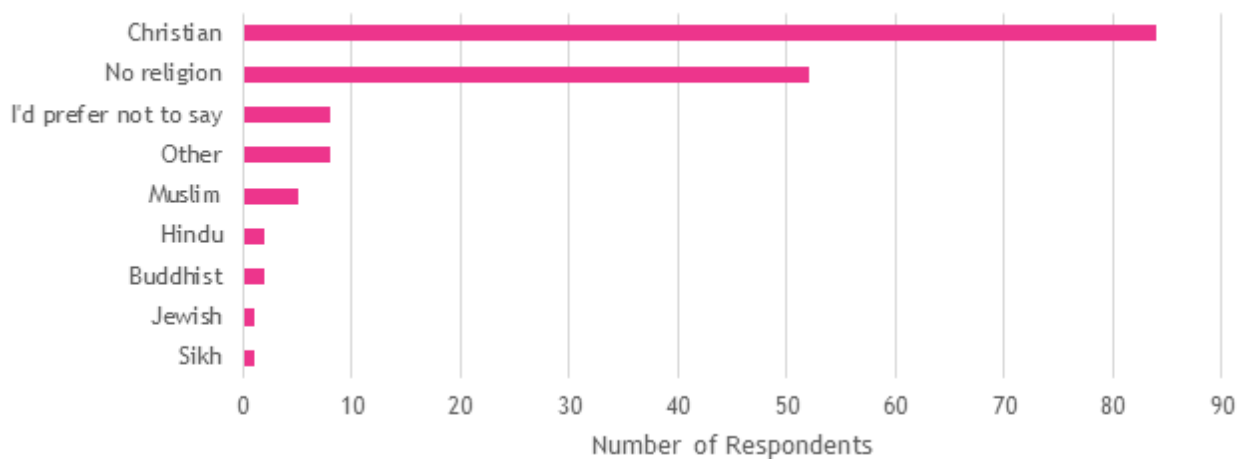
Appendix A: Demographic characteristics of survey respondents



General Survey - Bedford Borough - 176 responses [blanks are excluded from all charts]

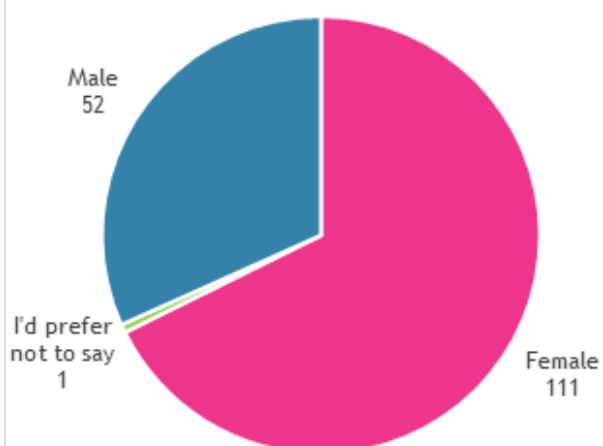


General Survey - Religion (BB)



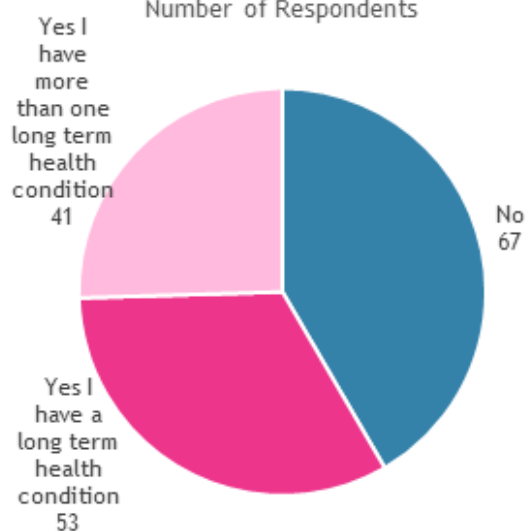
General Survey - Gender (BB)

Number of Respondents



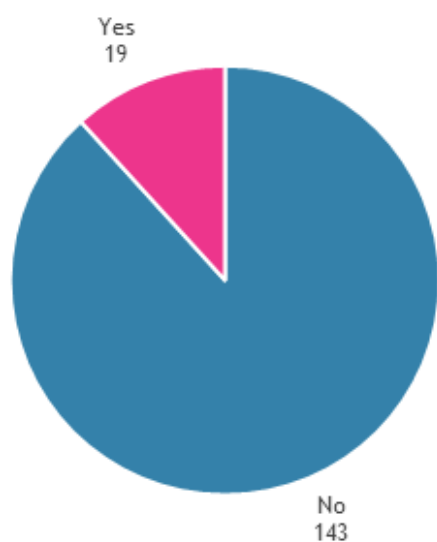
General Survey - Long term health condition (BB)

Number of Respondents



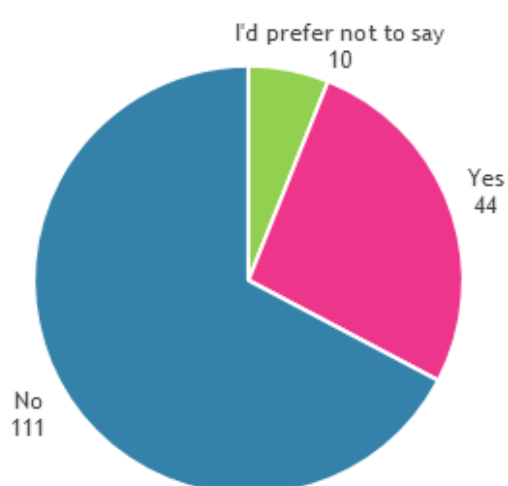
General Survey - Carer (BB)

Number of Respondents

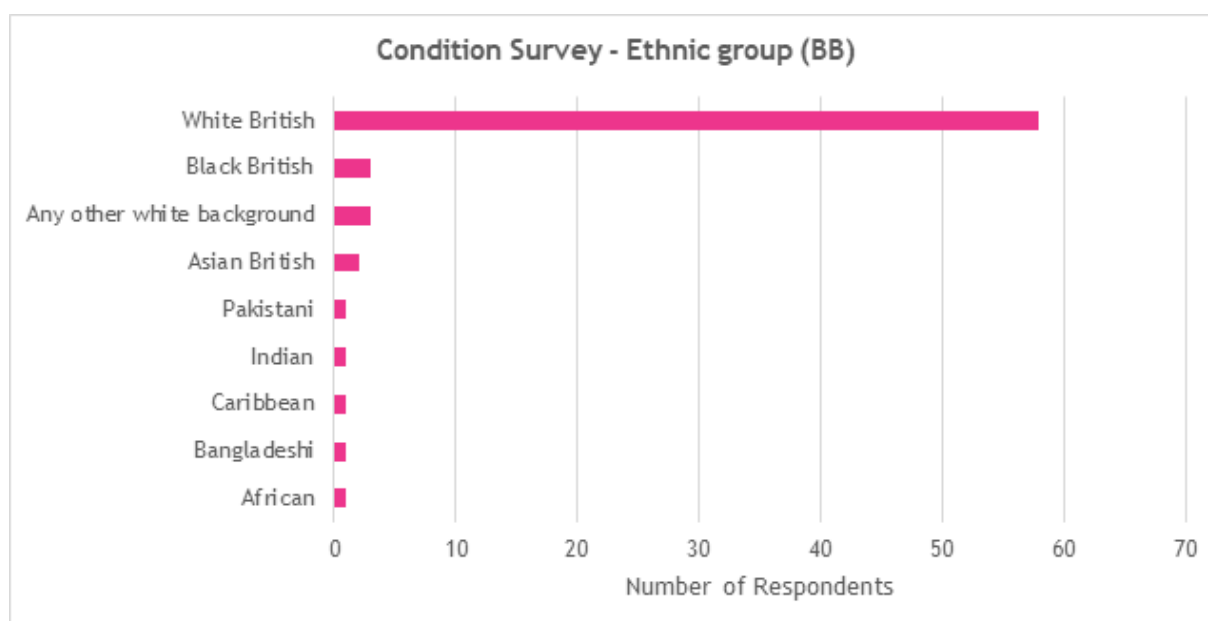
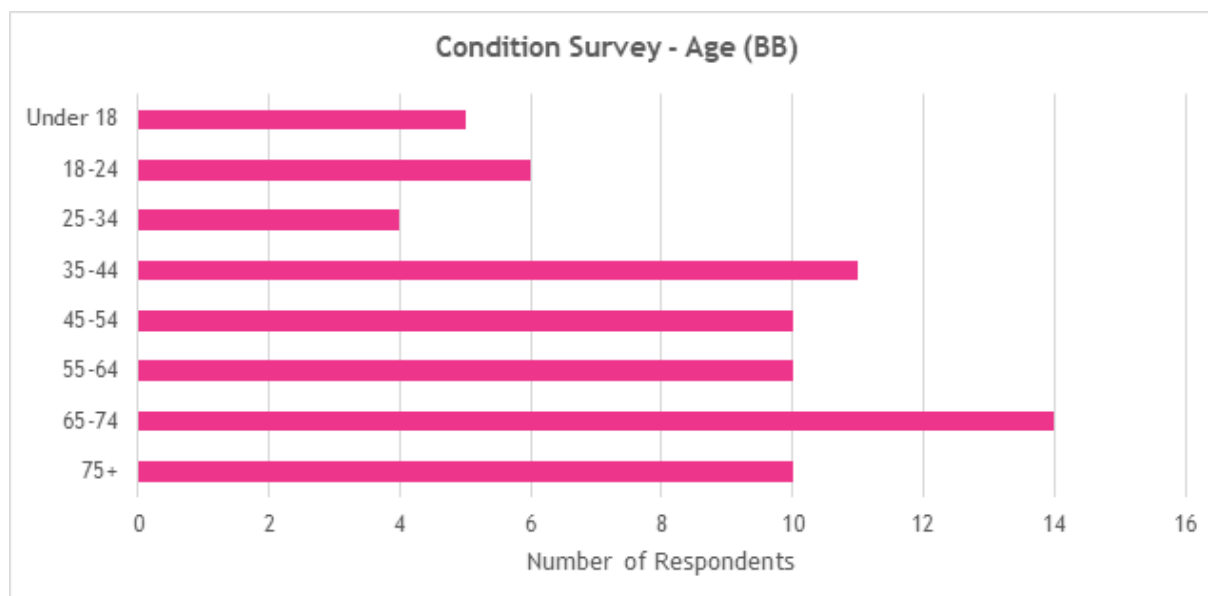
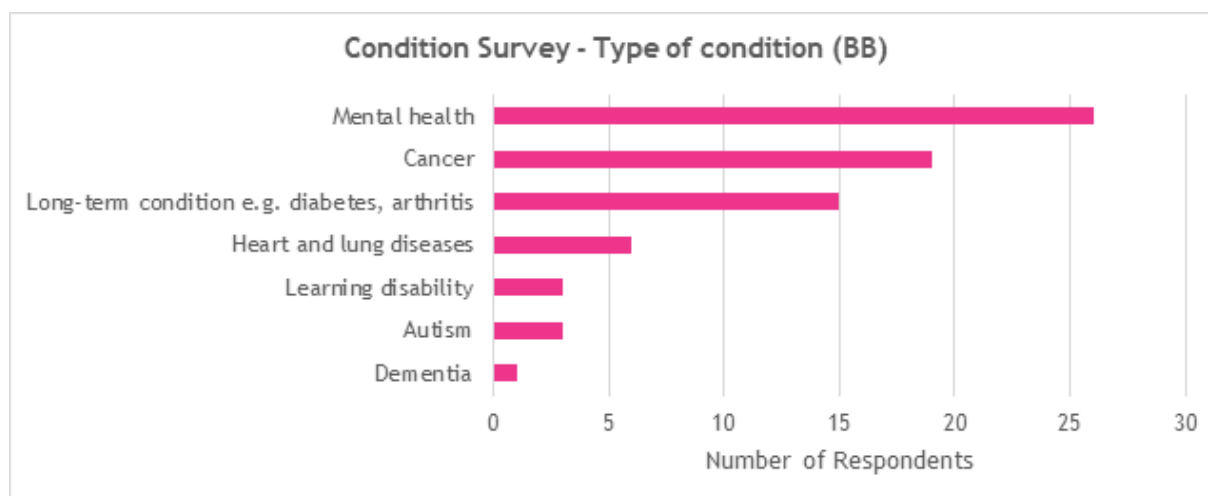


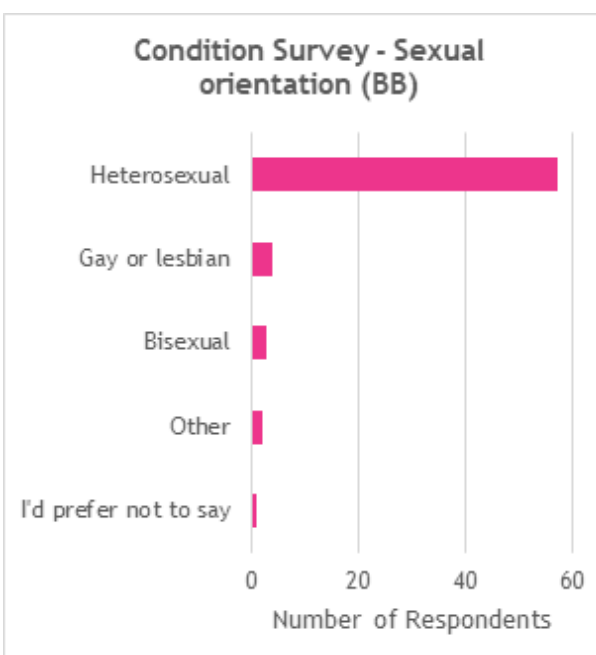
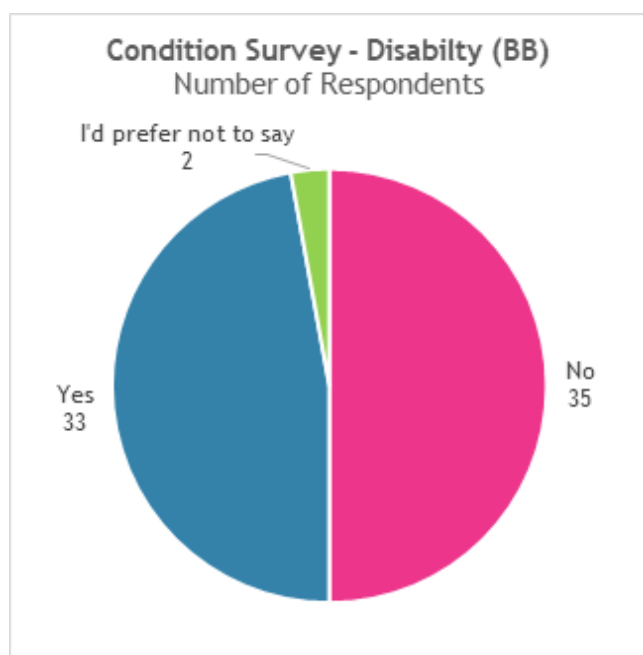
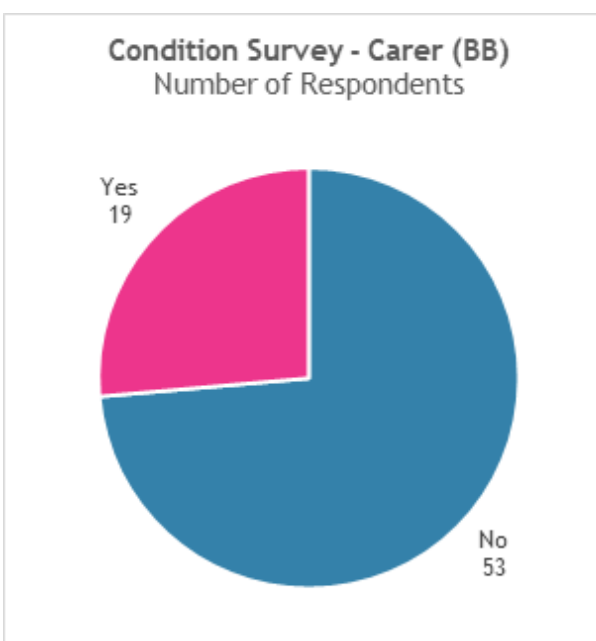
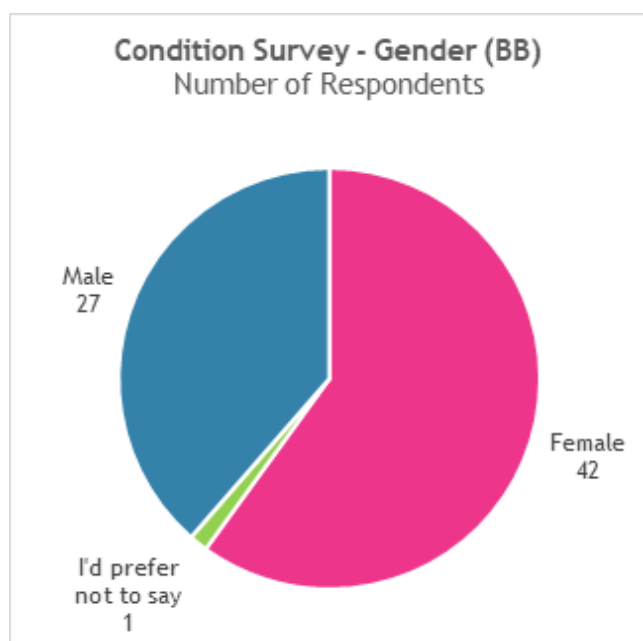
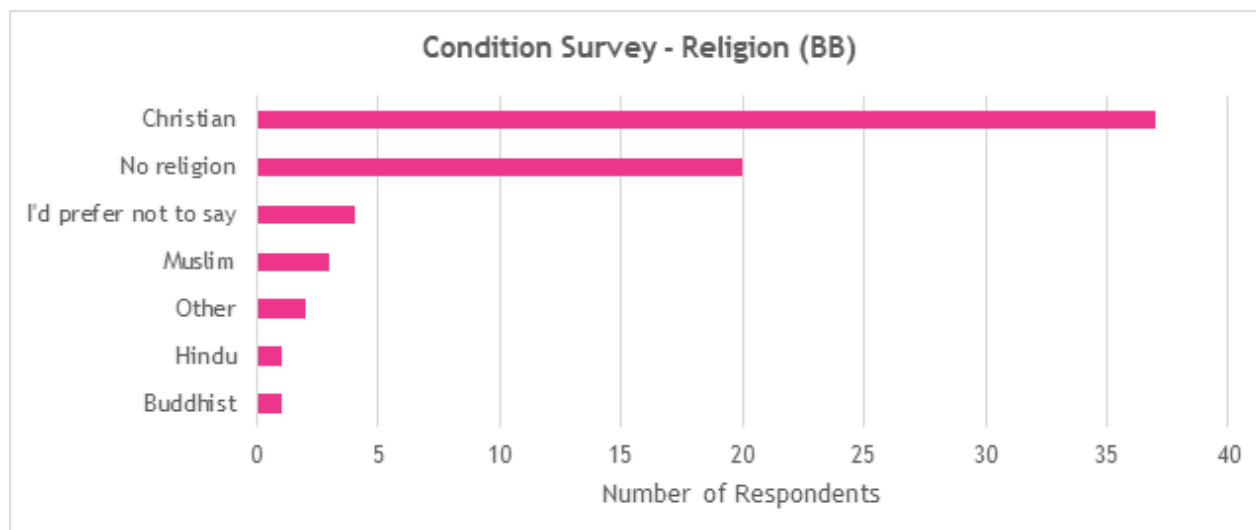
General Survey - Disability (BB)

Number of Respondents

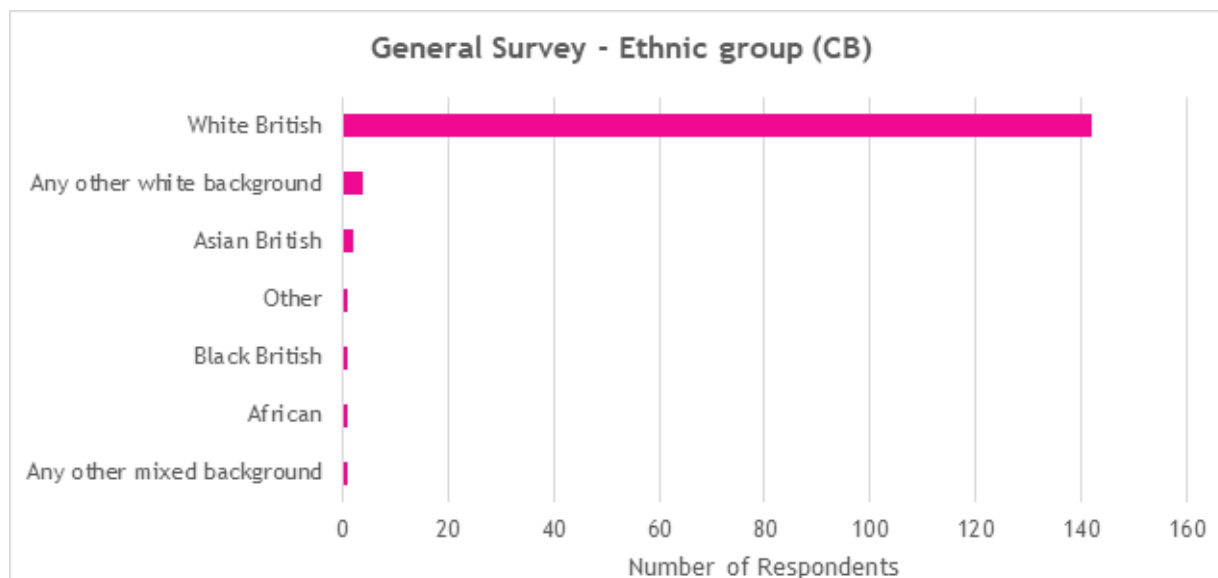
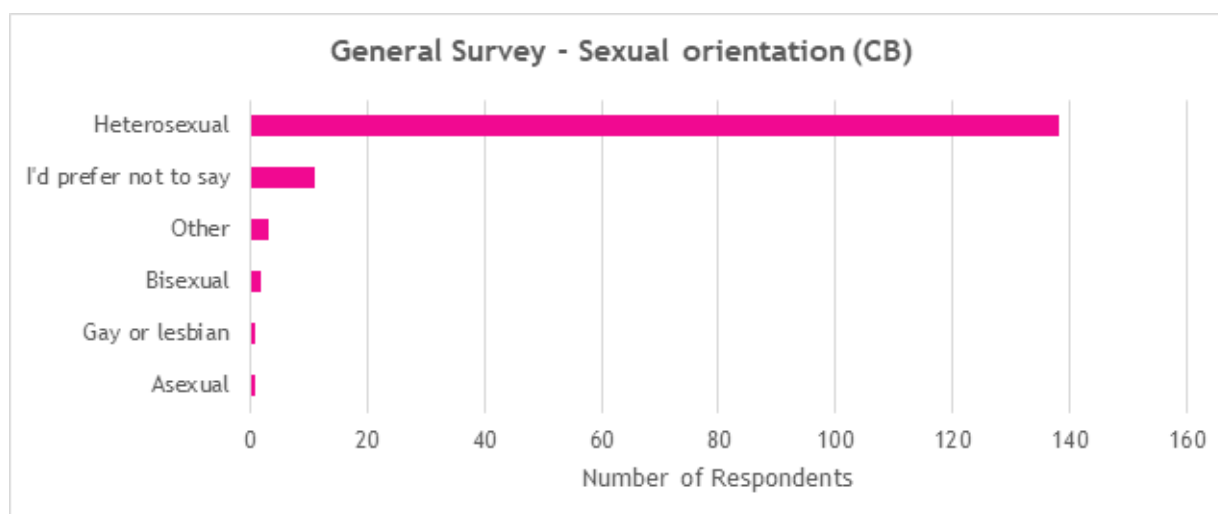
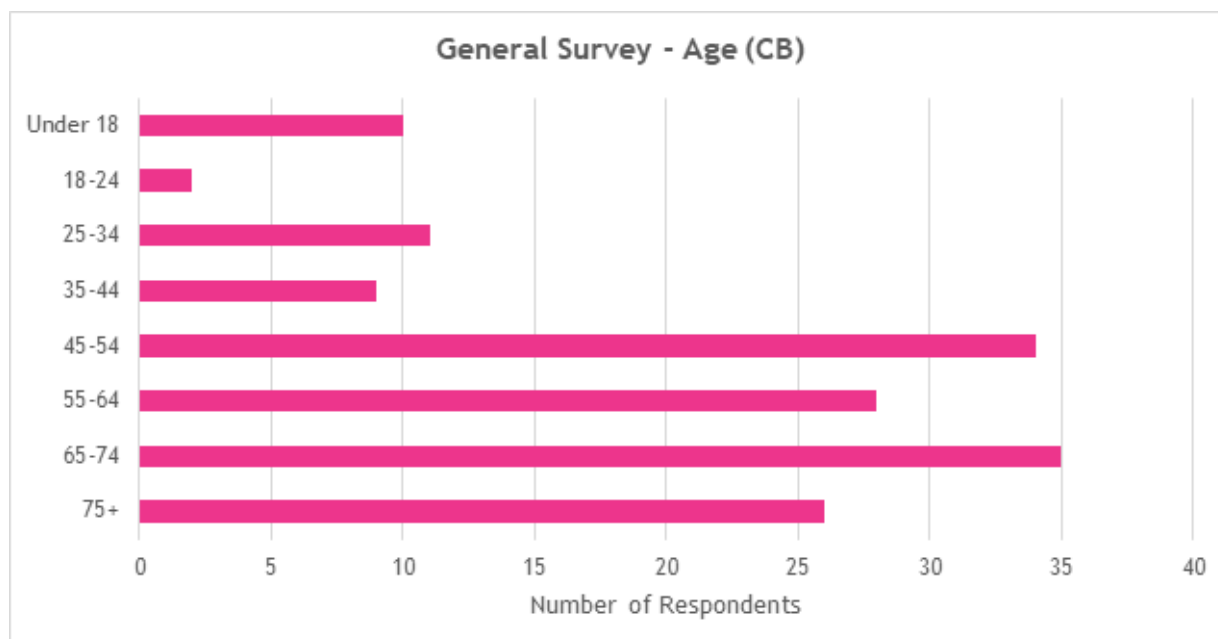


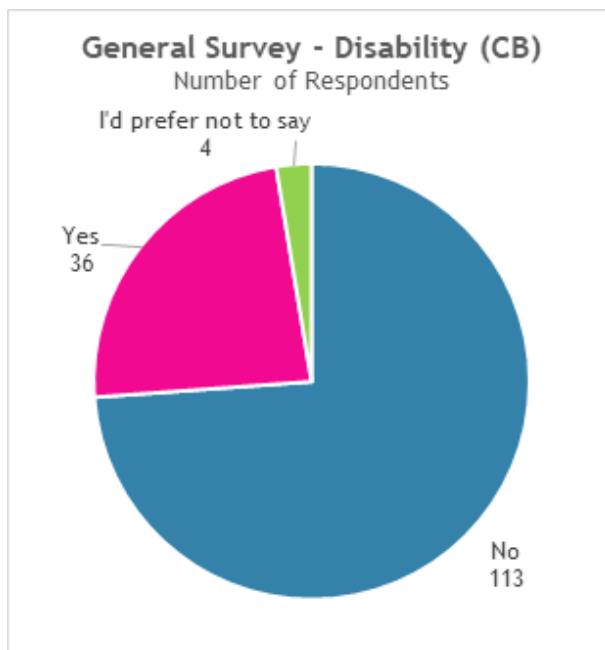
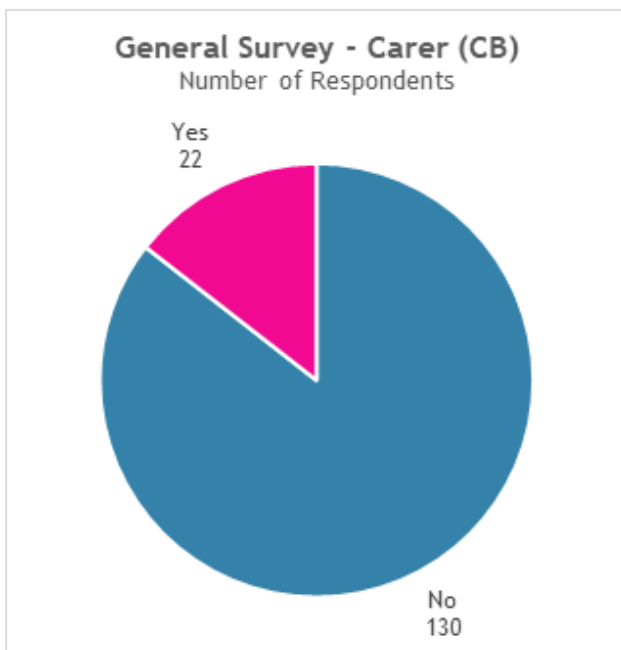
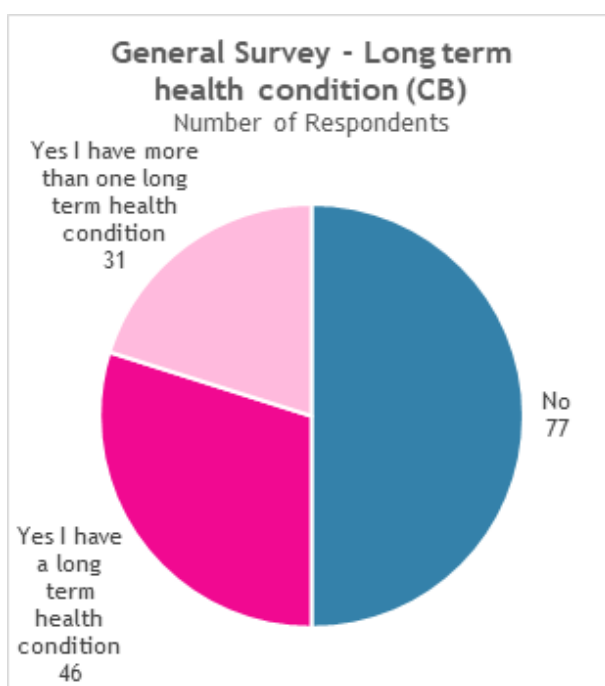
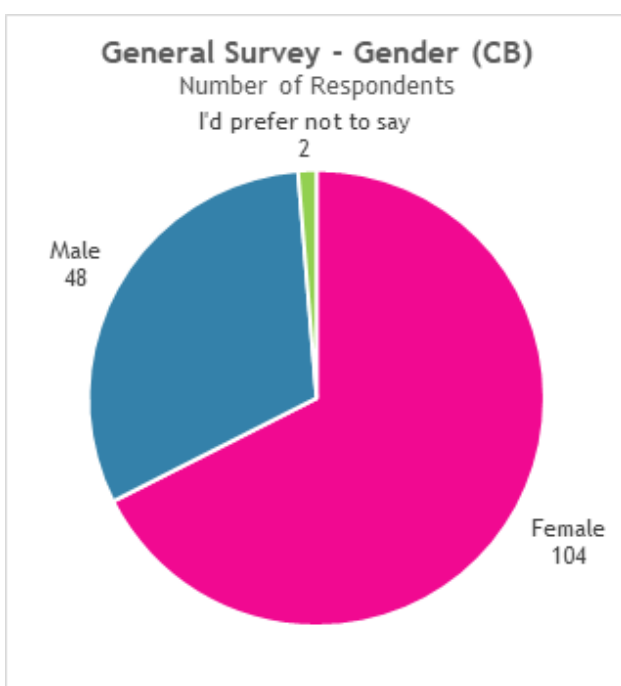
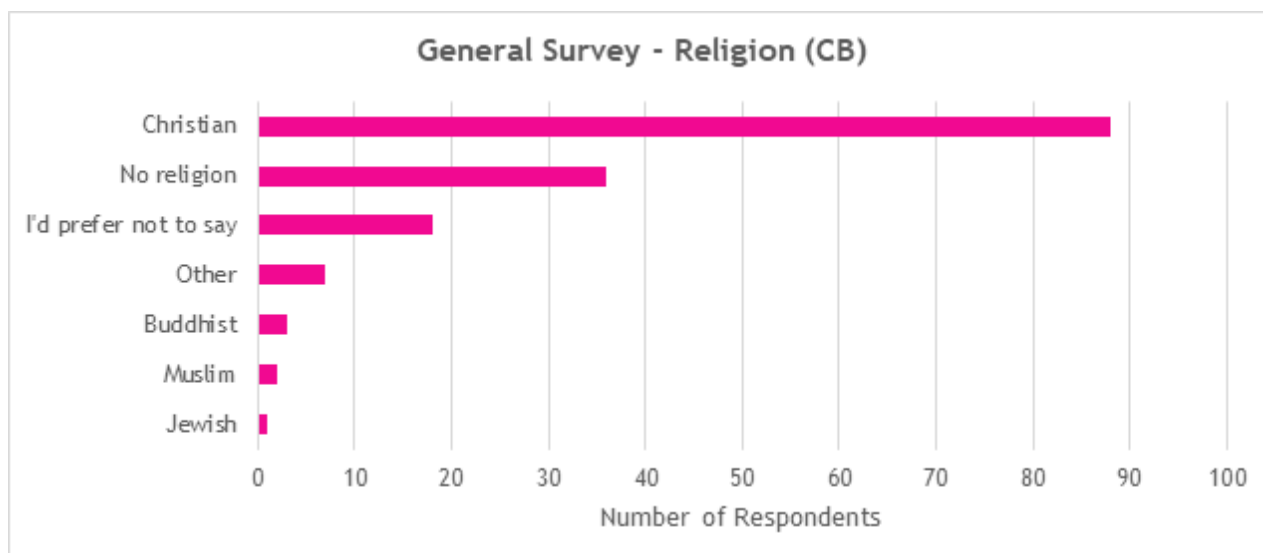
Condition Survey - Bedford Borough - 73 responses [blanks are excluded from all charts]





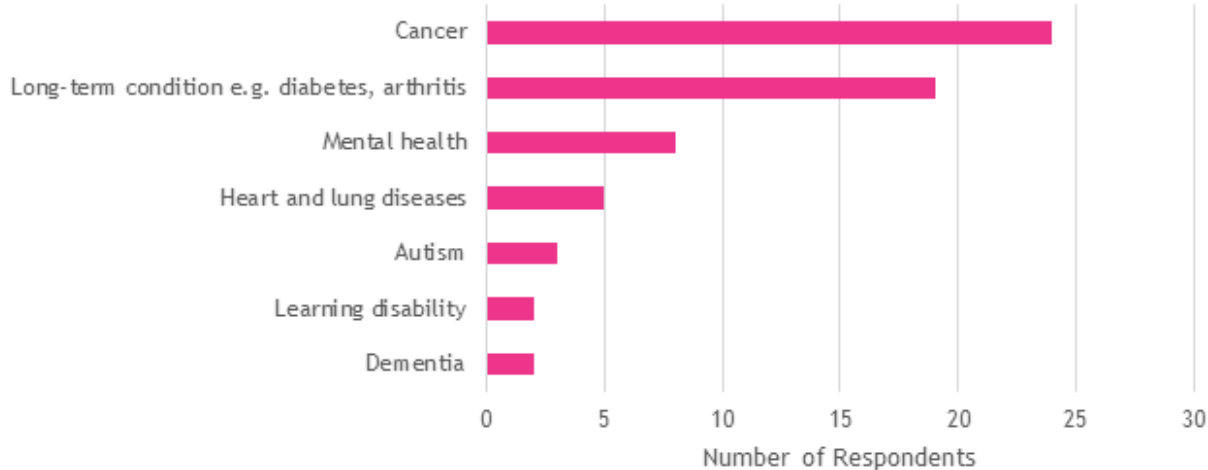
General Survey - Central Bedfordshire - 156 responses [blanks are excluded from all charts]



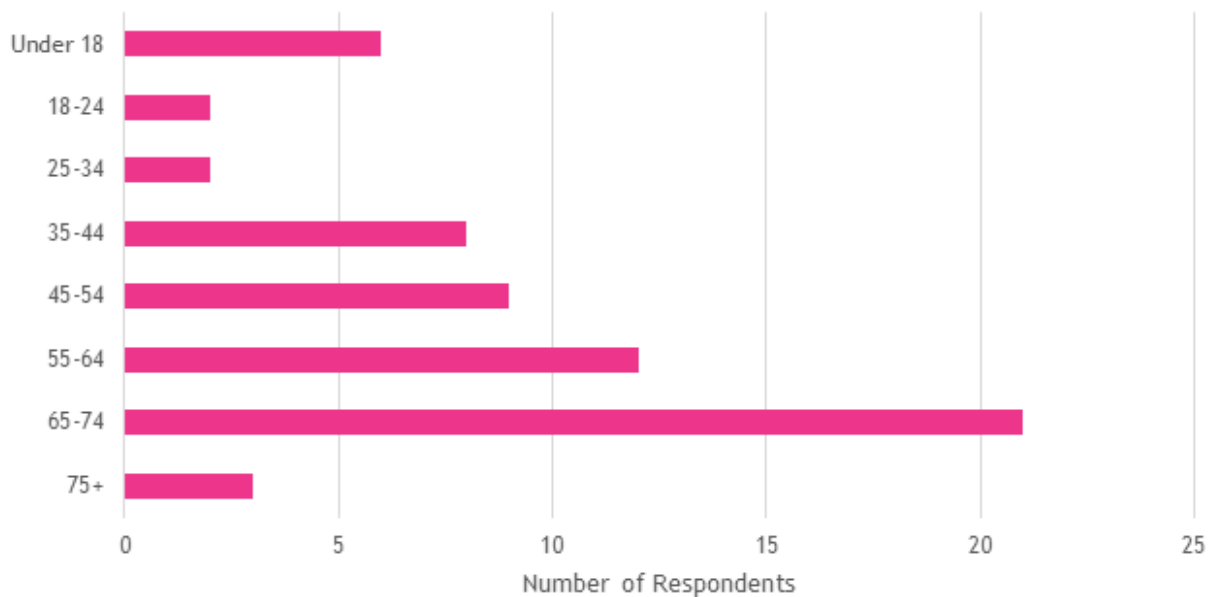


Condition Survey - Central Bedfordshire - 63 responses [blanks are excluded from all charts]

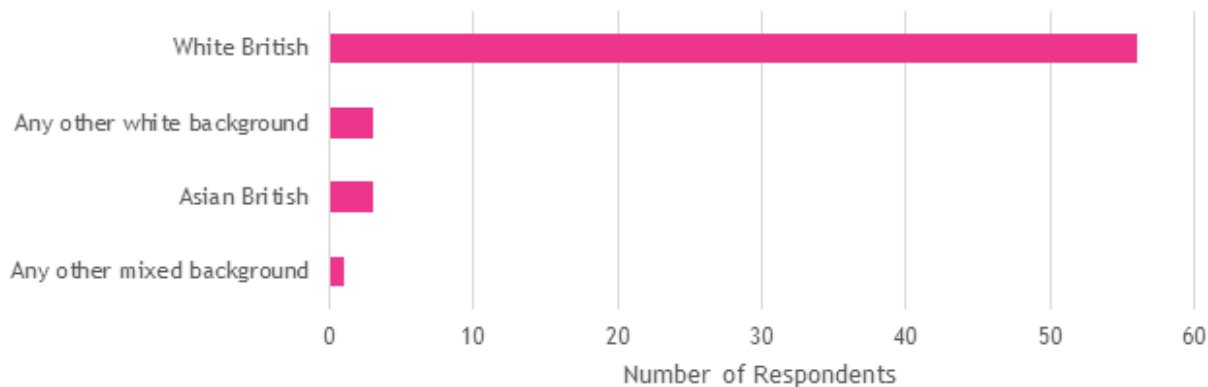
Condition Survey - Type of condition (CB)

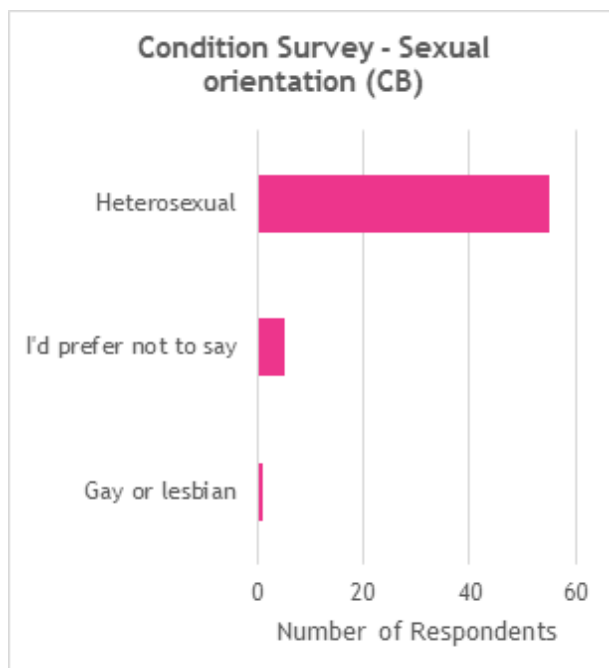
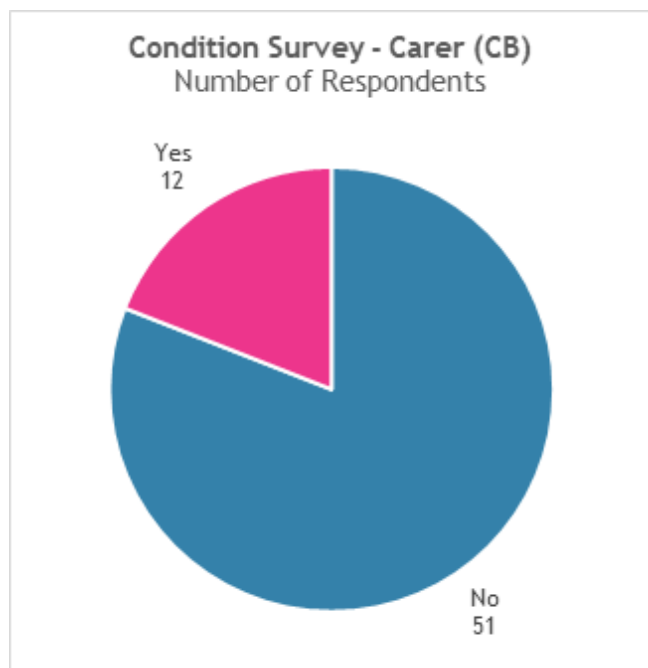
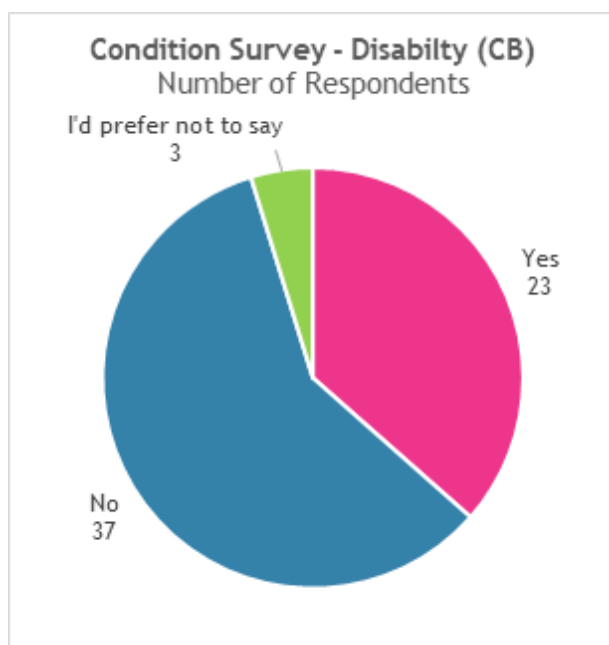
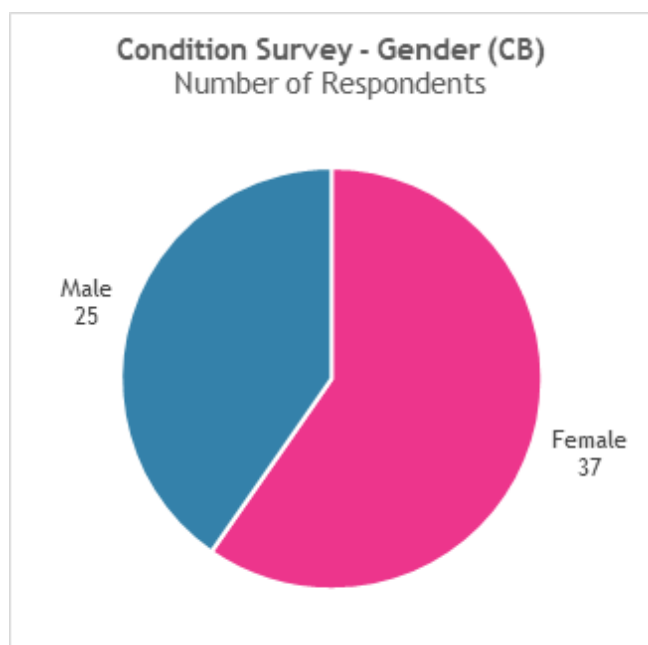
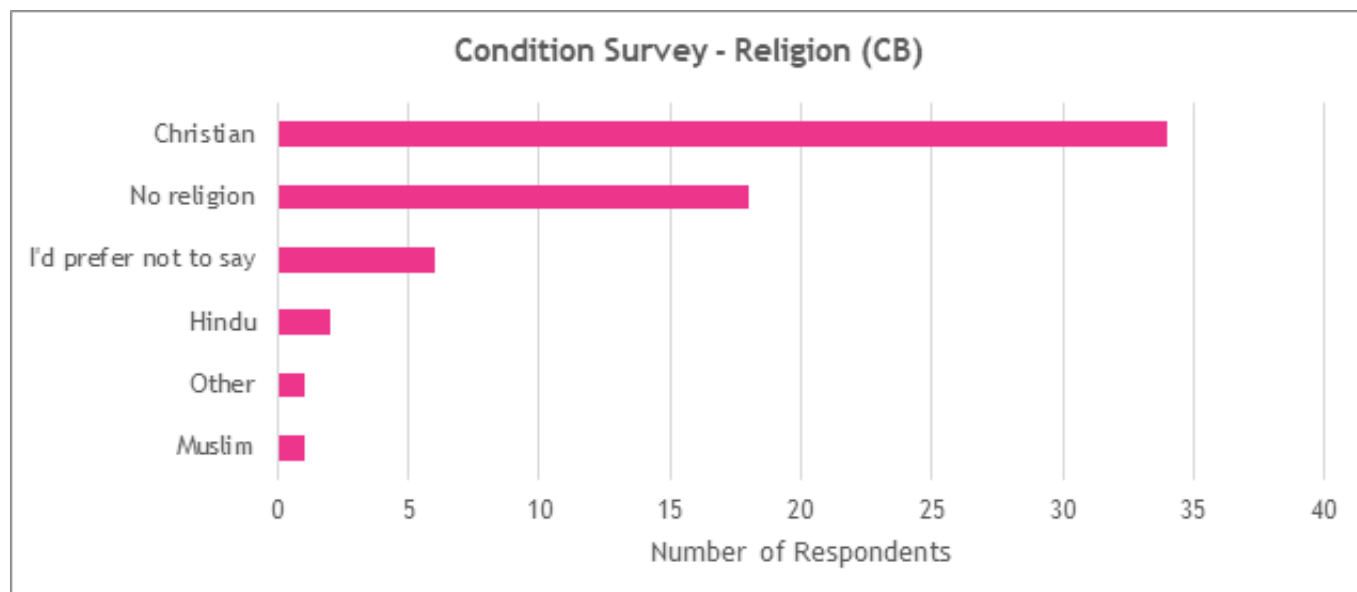


Condition Survey - Age (CB)

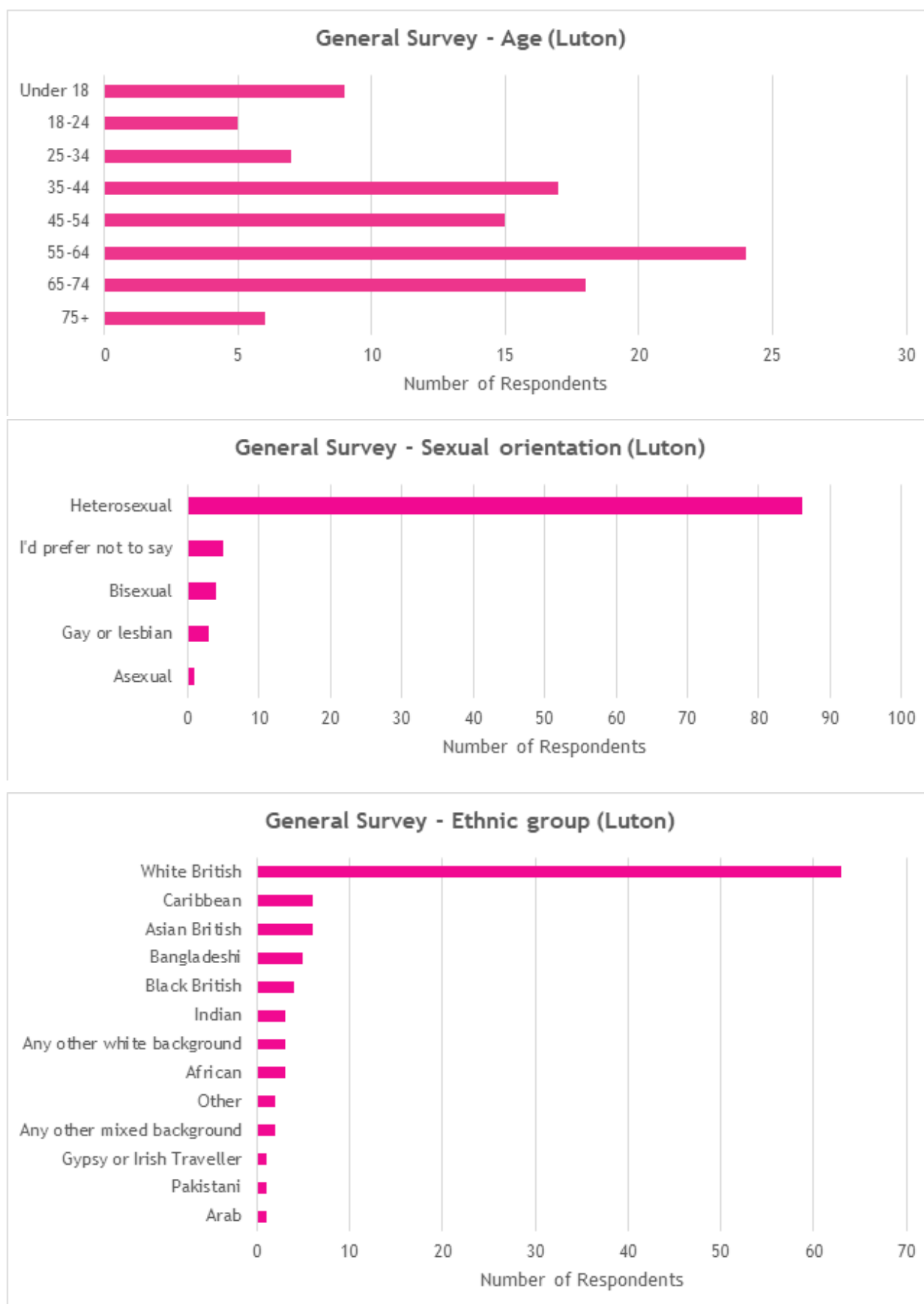


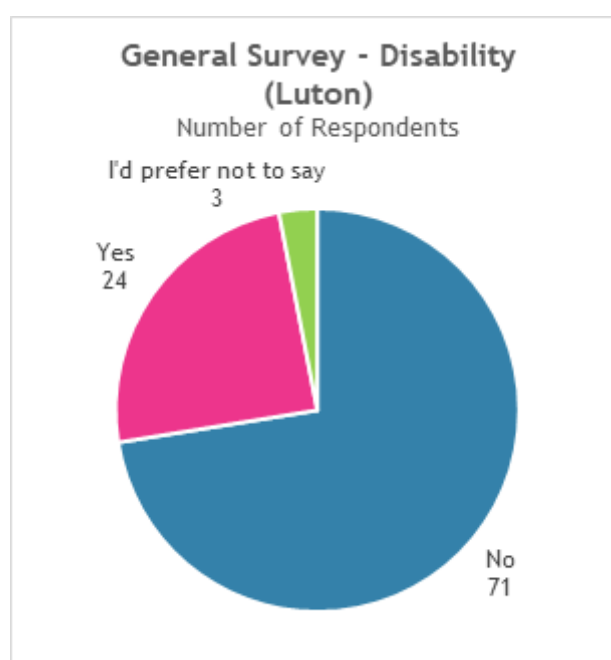
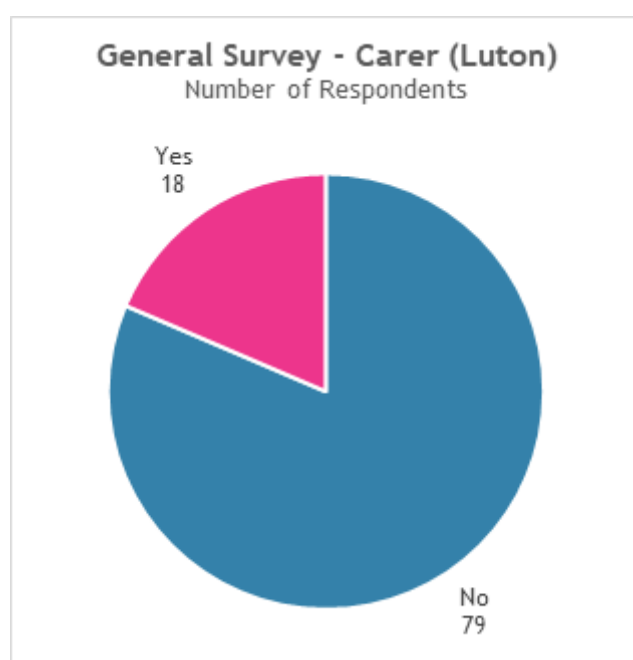
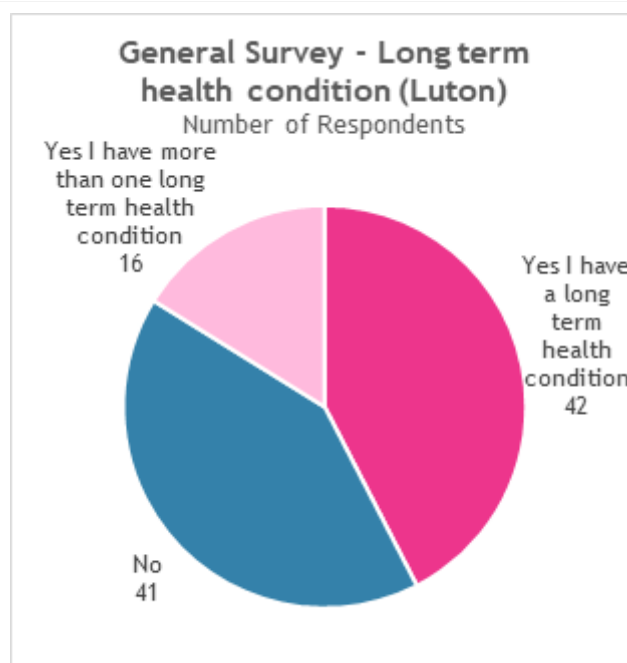
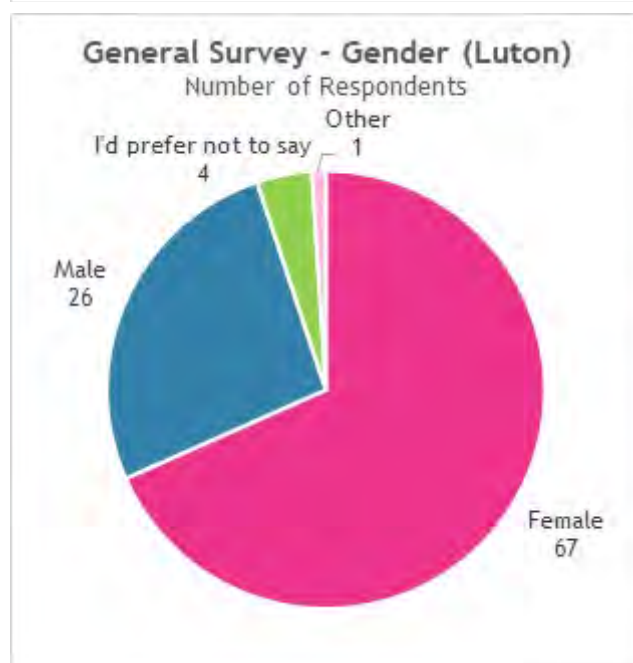
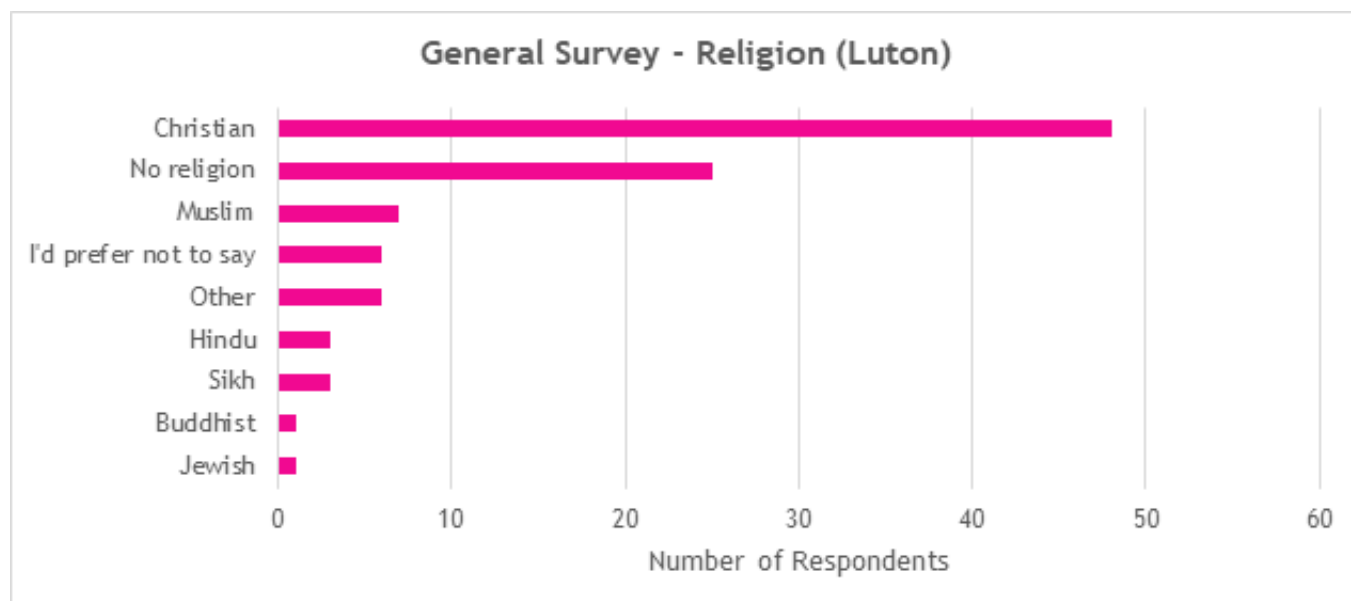
Condition Survey - Ethnic group (CB)





General Survey - Luton - 102 responses [blanks are excluded from all charts]

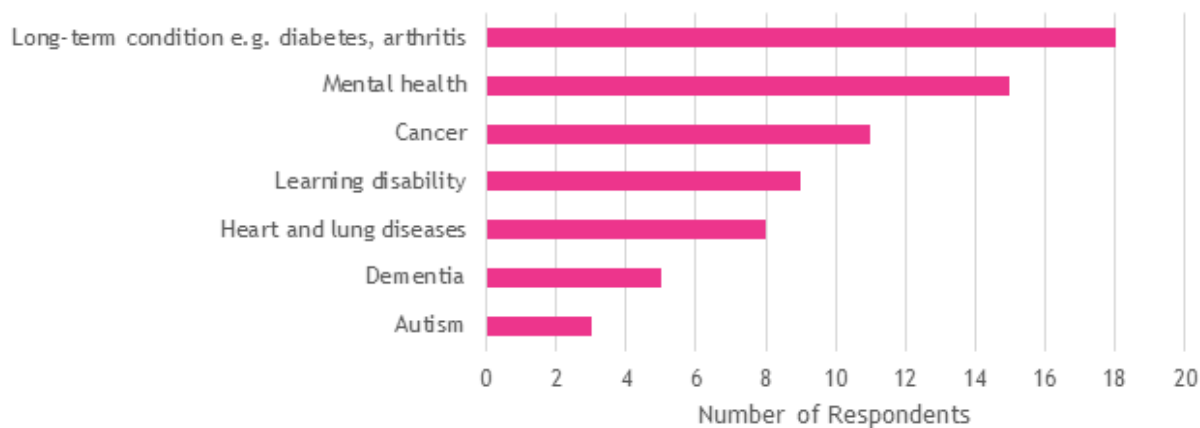




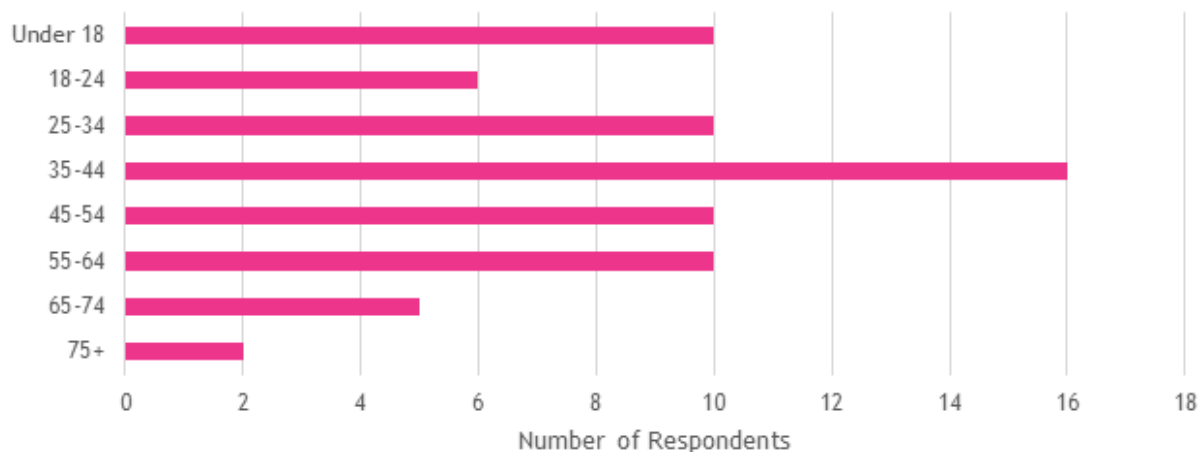
Condition Survey - Luton - 69 responses

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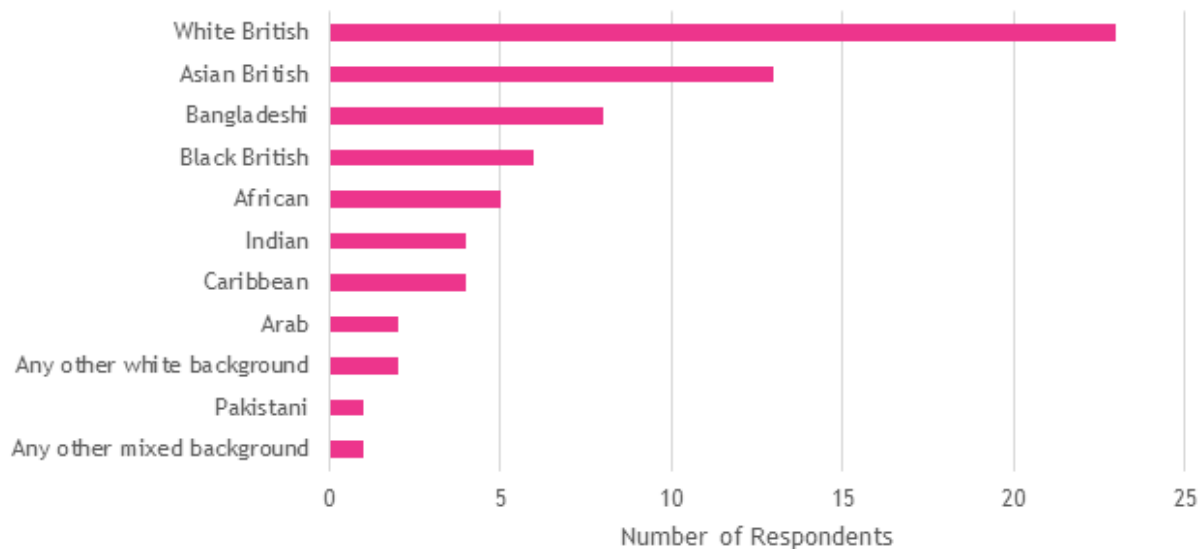
Condition Survey - Type of condition (Luton)

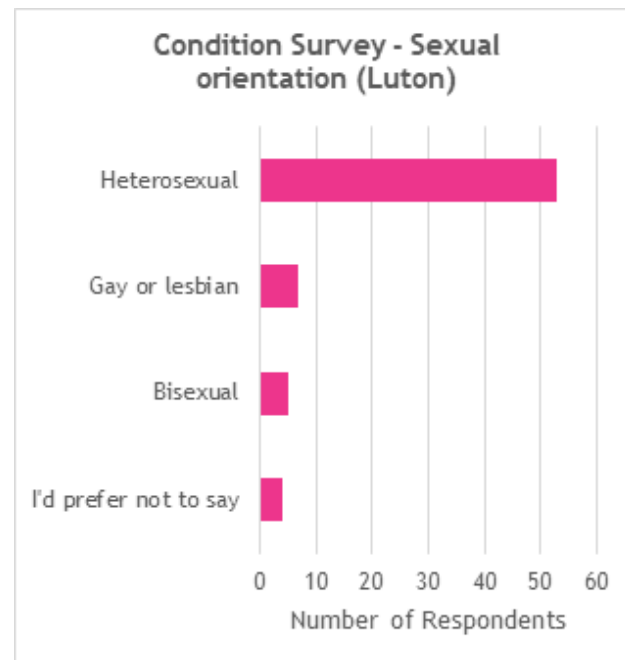
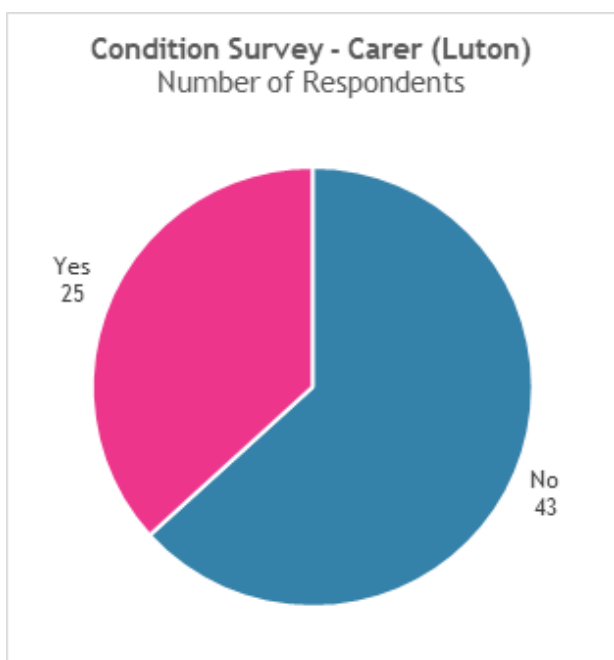
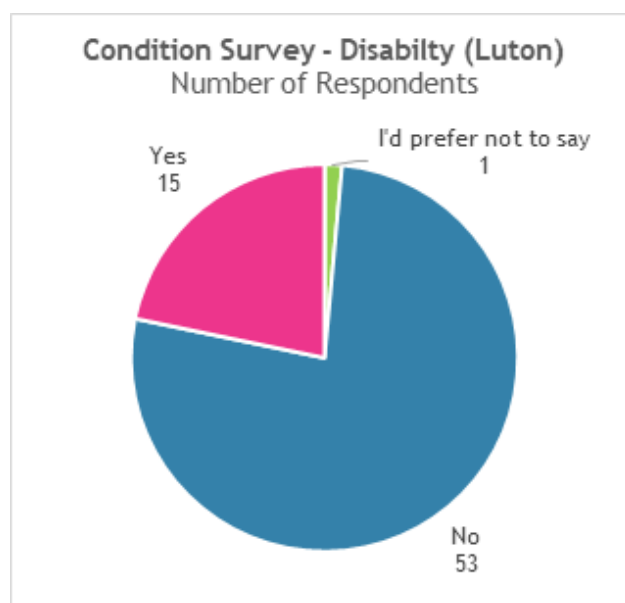
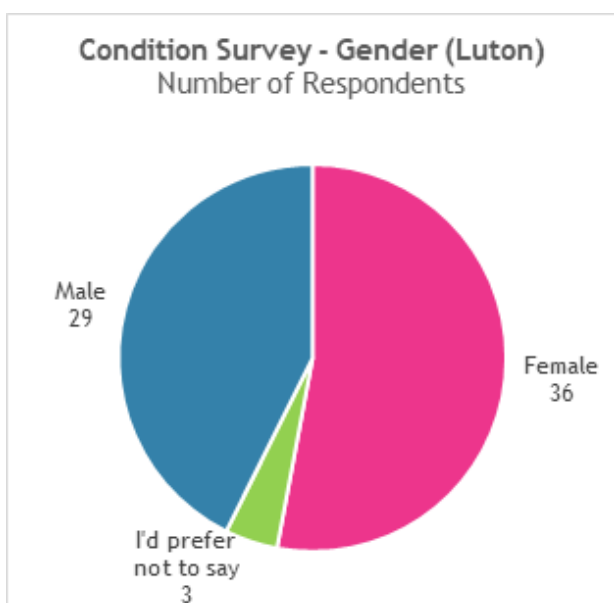
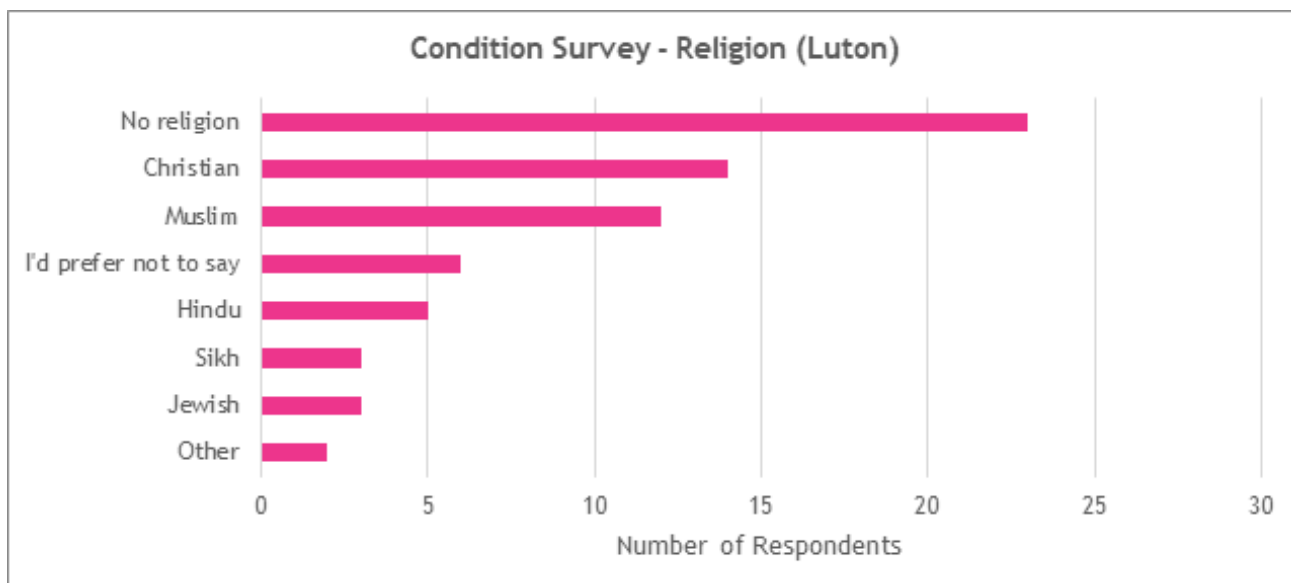


Condition Survey - Age (Luton)

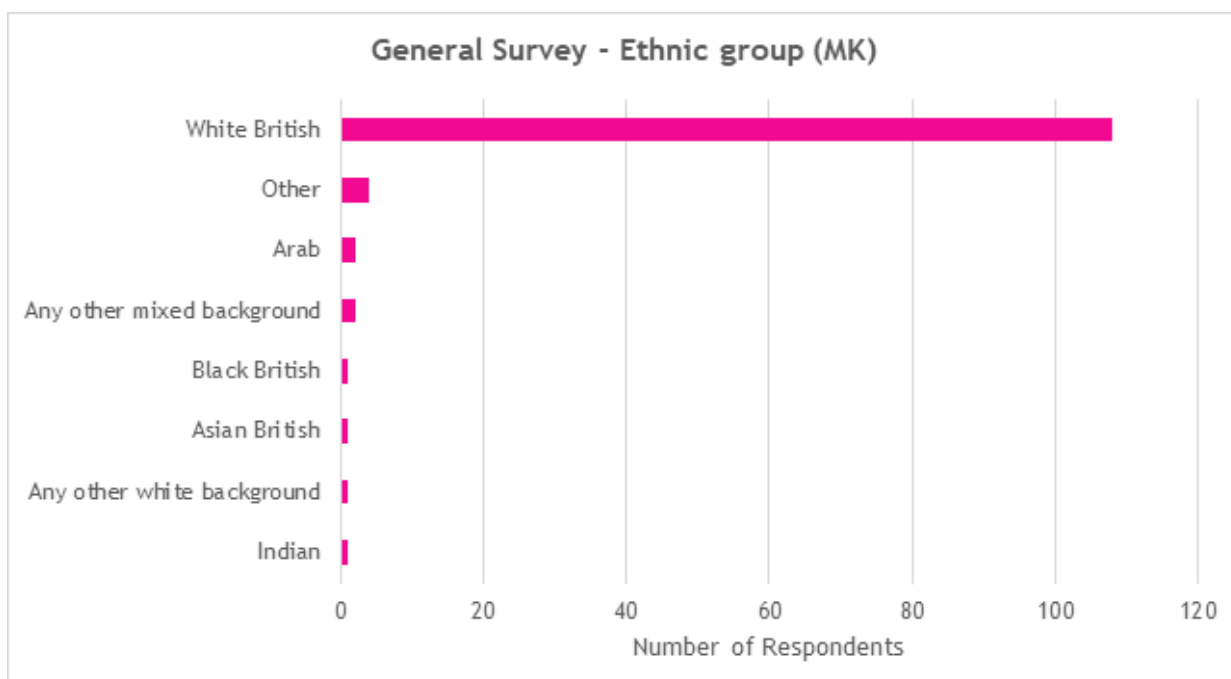
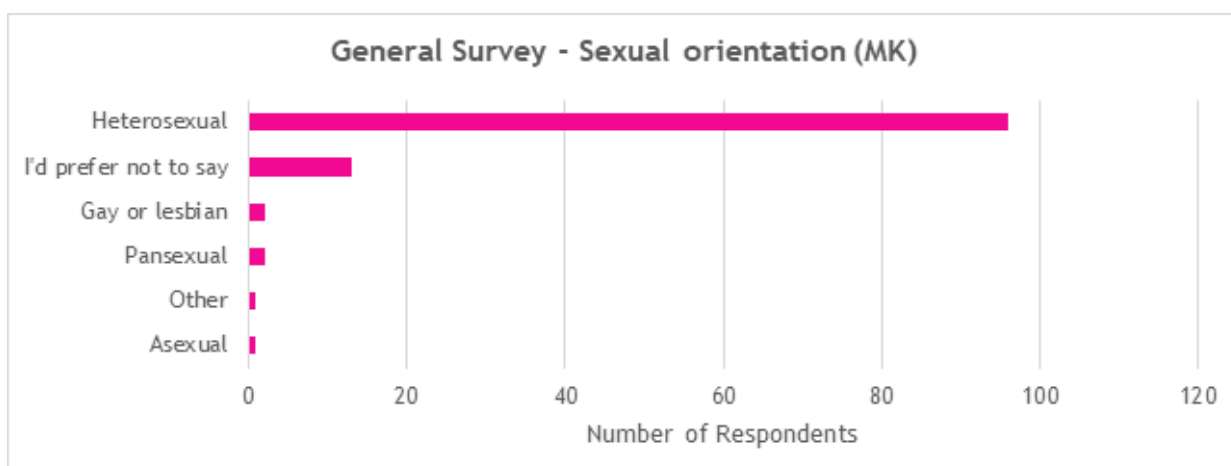
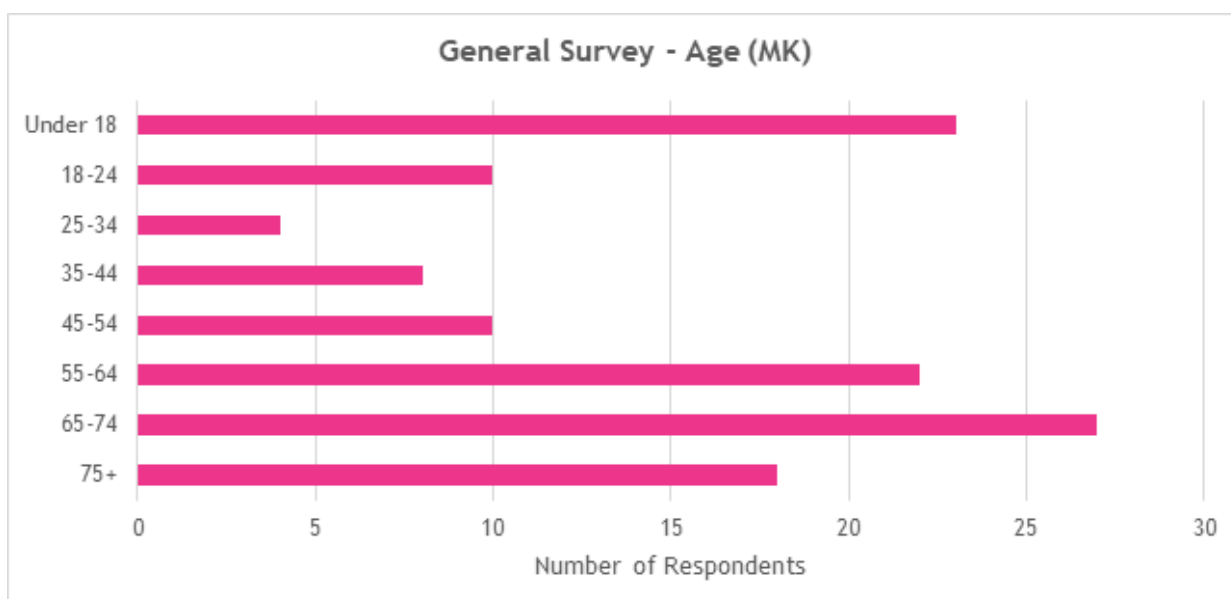


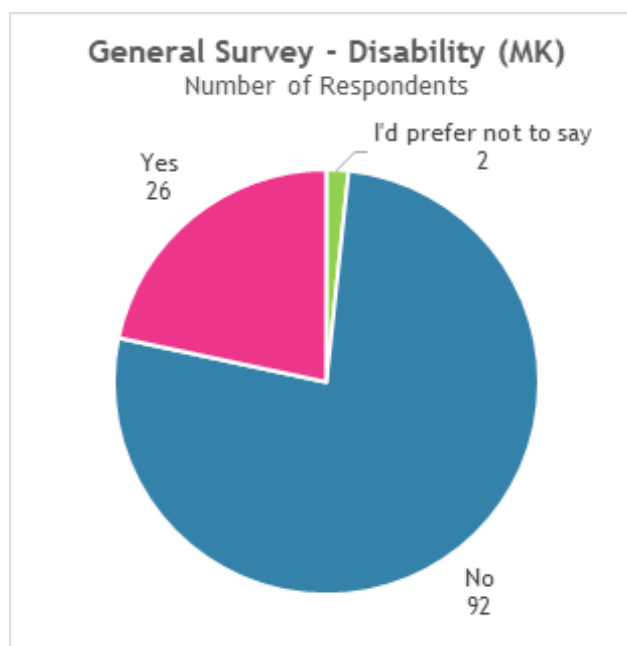
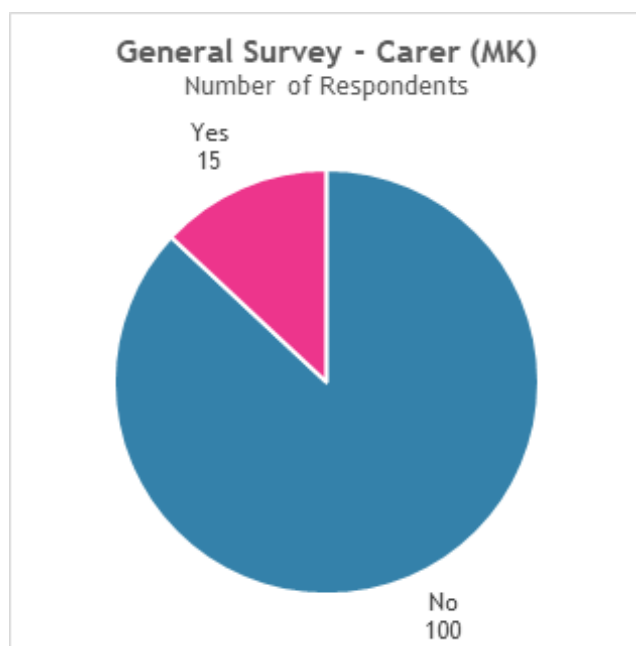
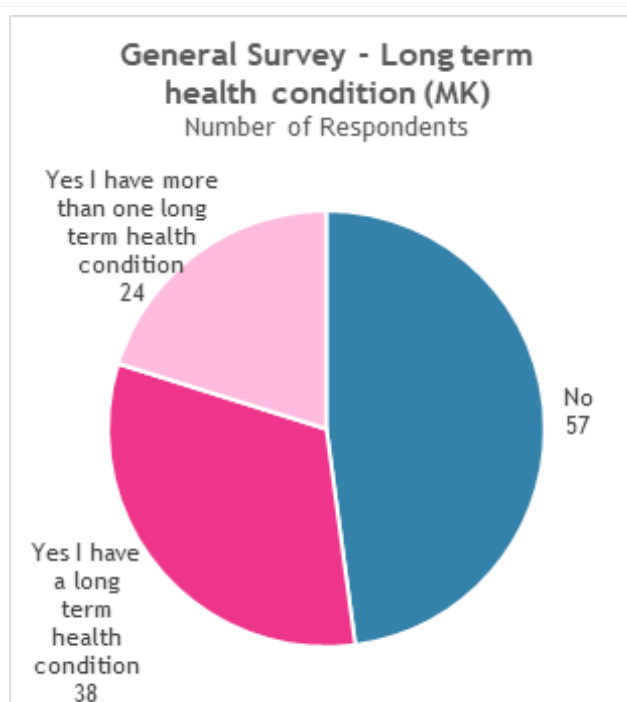
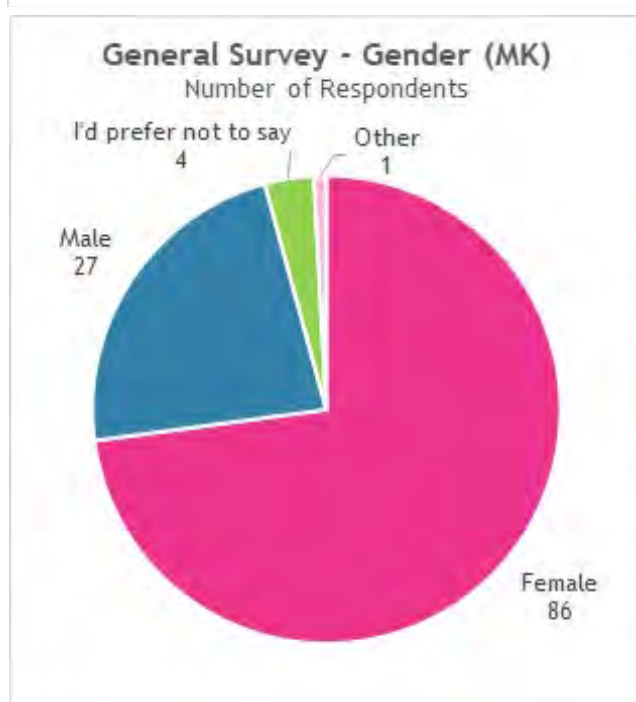
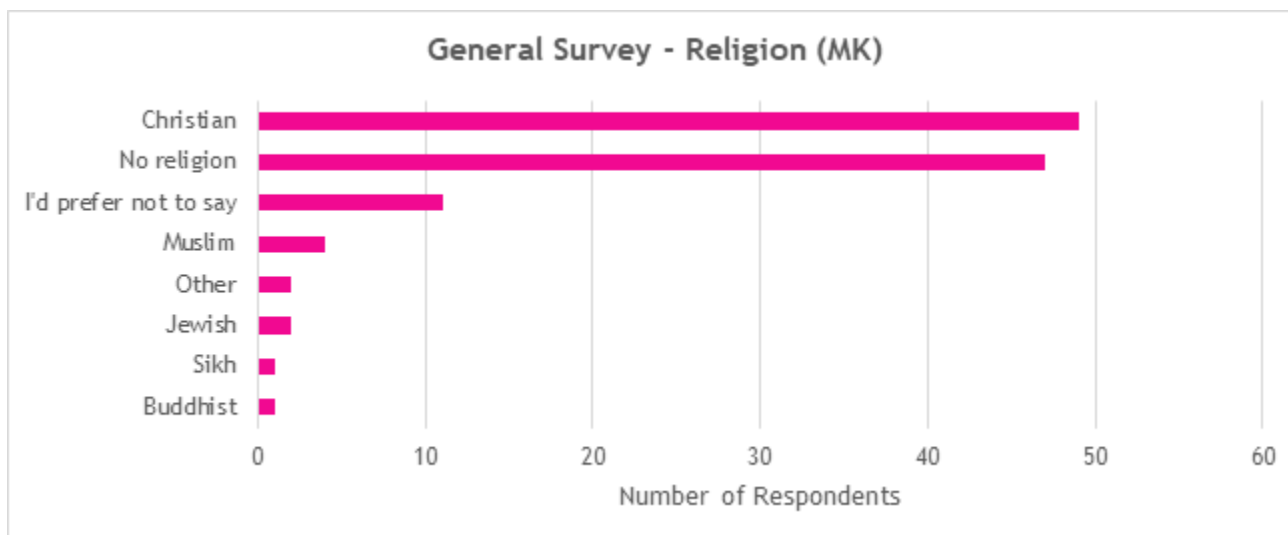
Condition Survey - Ethnic group (Luton)



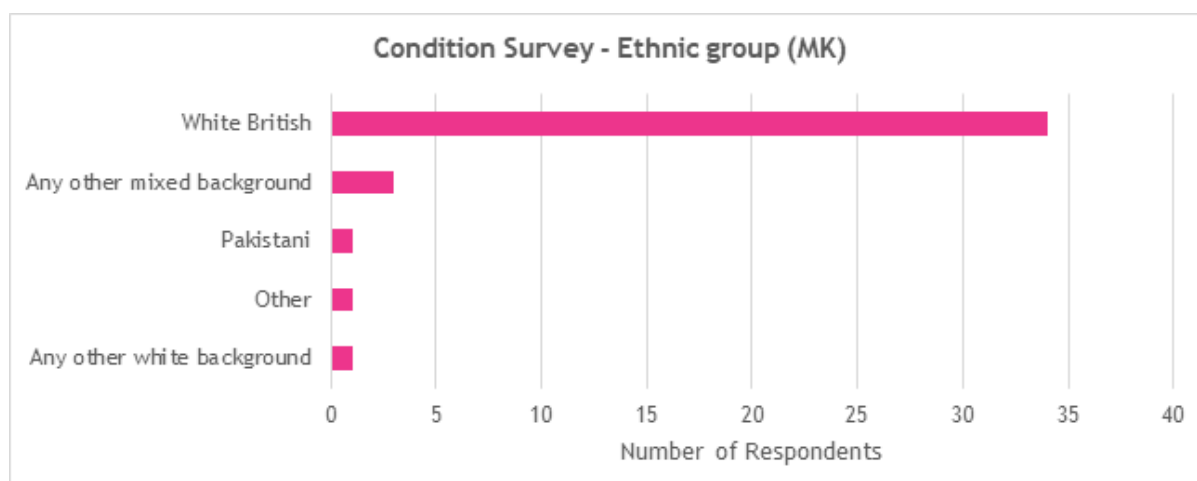
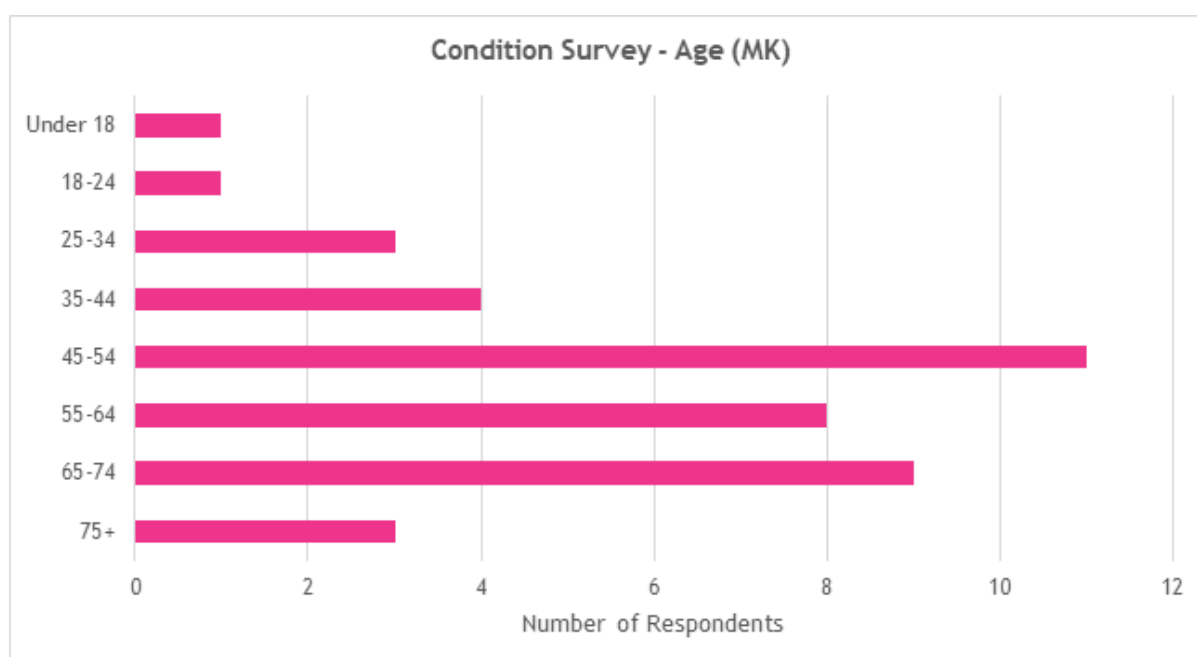
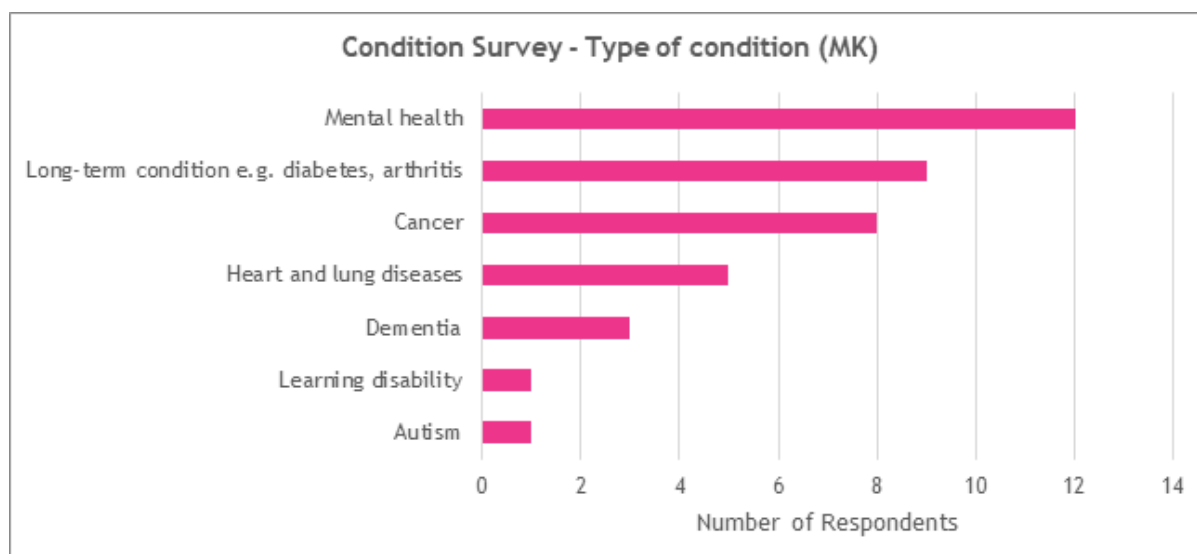


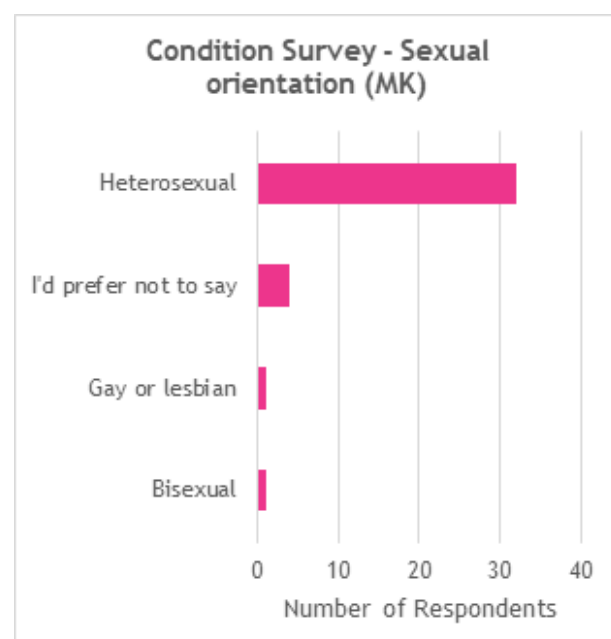
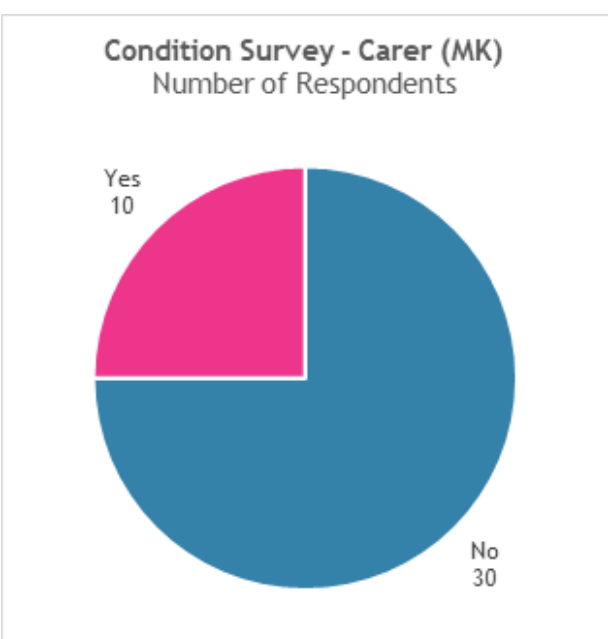
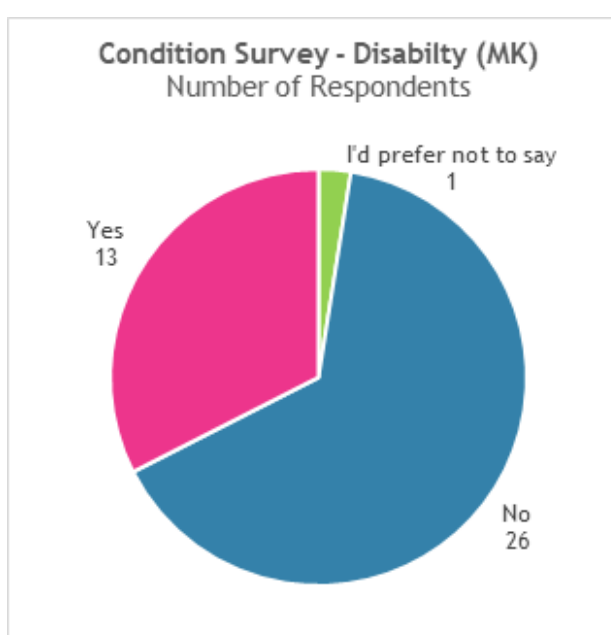
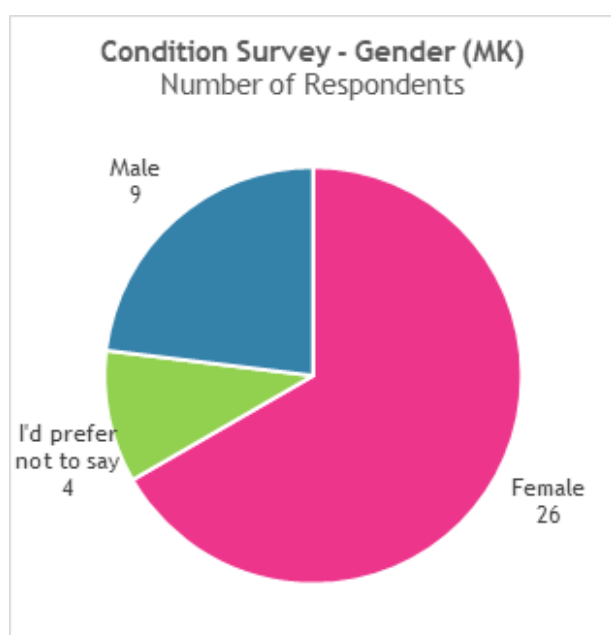
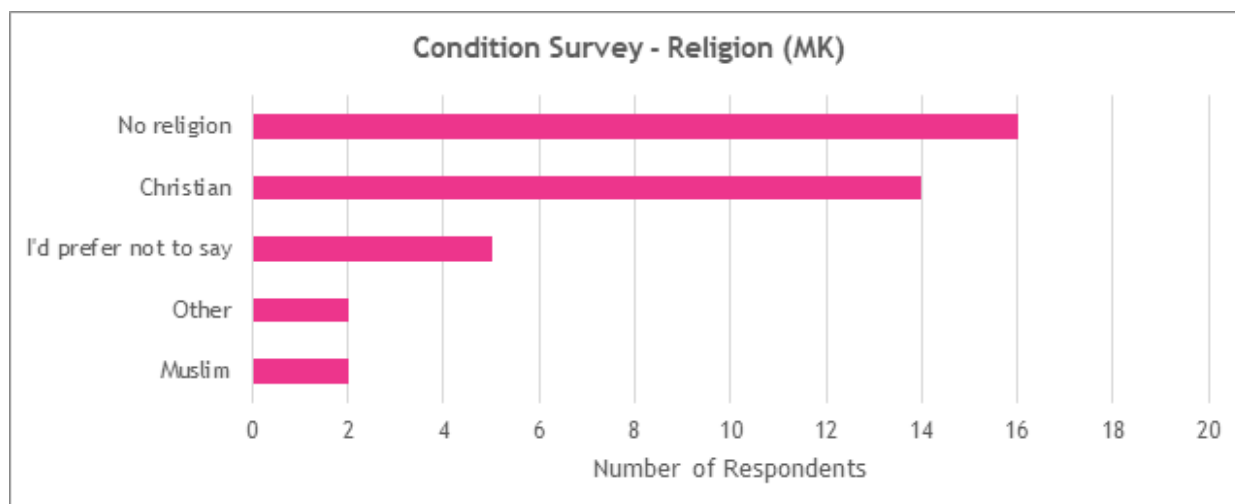
General Survey - Milton Keynes - 122 responses [blanks are excluded from all charts]





Condition Survey - Milton Keynes - 40 responses [blanks are excluded from all charts]





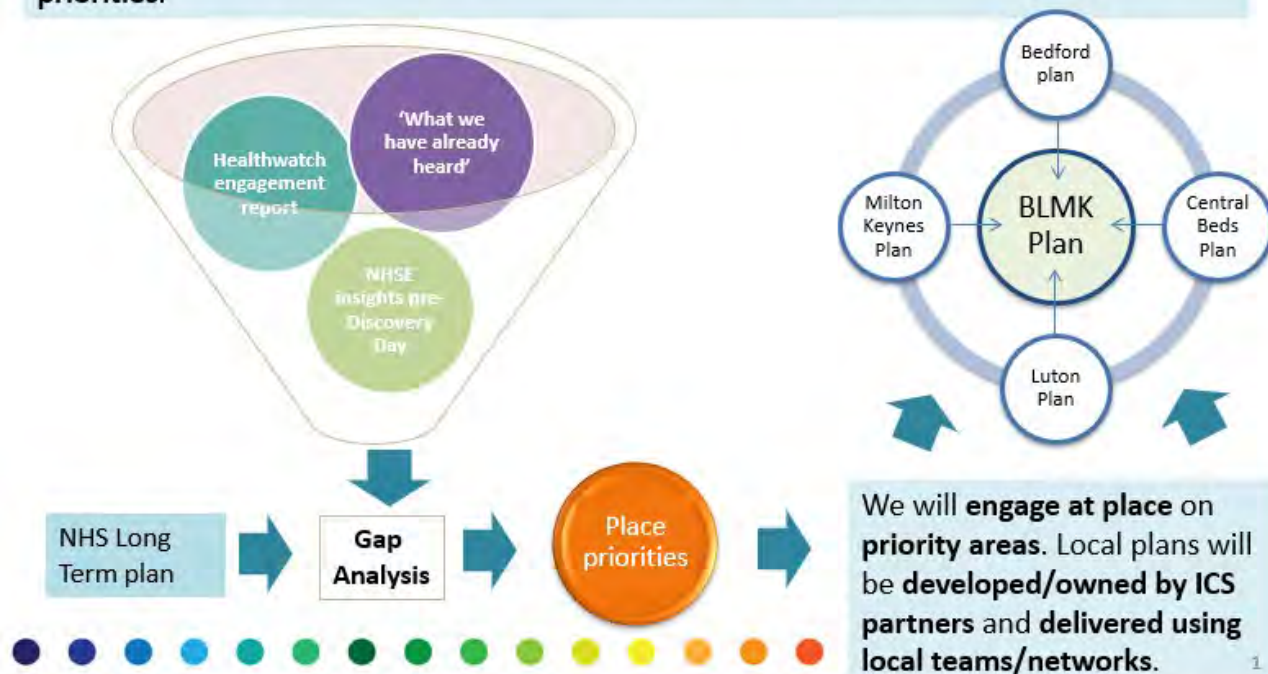


Appendix B: BLMK ICS Engagement Approach

Engagement approach



Our BLMK health and wellbeing long term plan will be **informed and co-designed** by those living in this area and focus on **what matters 'at place'** for our populations as well as **local priorities**.



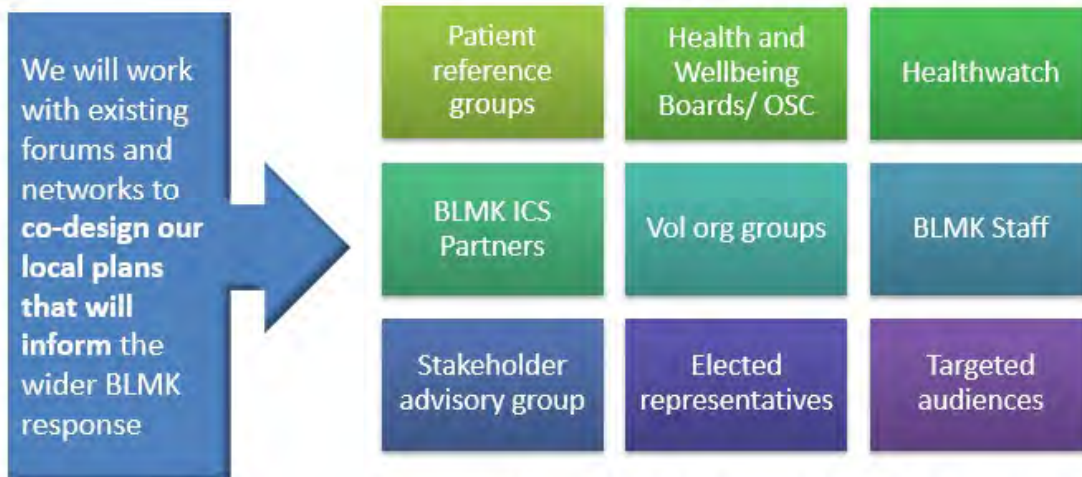
Agreed principles



We are proposing four principles that will underpin everything we do in developing longer term plans.

- 1. We think about residents' whole needs, not dealing with specific problems or issues in isolation.** We want to integrate care around individuals, not treat them as a list of ailments.
- 2. We care as much about what keeps us healthy as how to sort out the things that make us unwell.** We should be focusing on wellness not illness, helping people live longer lives in good health.
- 3. We will aim to improve access to quality local health and care services.** This will be at home, in our communities and, where absolutely necessary, in specialist settings such as hospitals.
- 4. We will develop and deliver plans for our future health and care services which provide value for money.** We will have an affordable, joined up and sustainable system.

Our approach



We will build on work already in progress and **continue with this engagement approach throughout delivery** of the NHS Long Term Plan.

3

Local conversations



Local conversations will **build on what we already know** and capture feedback on specific areas (see next slide) and general themes about **'What matters to you'** during discussions.



4

Proposed specific areas of focus across BLMK



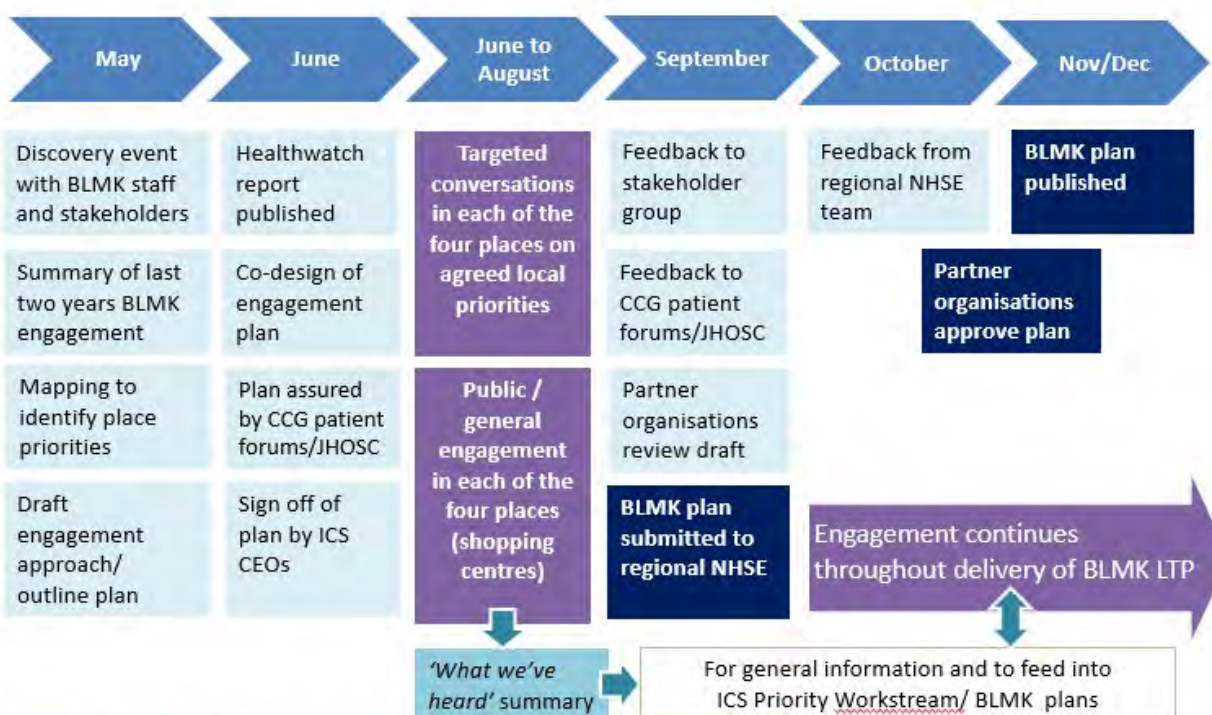
The NHS Long Term plan adds on another layer to place plans. Planning leads across BLMK are currently reviewing priority areas to identify the top systemic issues to focus on – see below initial thoughts:

- Cancer
- Mental Health
- Primary care
- Non-elective (focus on prevention and pro-active care to keep people well and reduce the need for hospital treatment)

Each place may also have some additional issues they want to focus on e.g. Mayor of Bedford keen to consider diabetes/obesity.

5

Timeline



6

healthwatch Bedford Borough

21-23 Gadsby St
Bedford MK40 3HP

T: 01234 718018

www.healthwatchbedfordborough.co.uk

healthwatch Central Bedfordshire

Capability House, Wrest Park
Silsoe MK45 4HR

T: 0300 303 8554

www.healthwatch-centralbedfordshire.org.uk

healthwatch Luton

110 Great Marlings
Luton
LU2 8DL

T: 0300 068 3000

www.healthwatchluton.co.uk

healthwatch Milton Keynes

Suite 113 Milton Keynes Business Centre,
Foxhunter Drive
Milton Keynes MK14 6GD

T: 01908 698800

www.healthwatchmiltonkeynes.co.uk

NHS Long Term Plan Report - June 2019