BEDFORDSHIRE, LUTON AND MILTON KEYNES FOOTPRINT REPORT

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Bedfordshire, Luton and Milton Keynes Footprint Report
Executive Summary

Background

The Healthwatch network was funded by NHS England and NHS Improvement to carry out engagement with communities across the country to establish how the Long Term Plan (LTP) should be implemented at a local level. The views gathered will feed into the development of the NHS’ local Plans.

Almost one million people live within the BLMK area which includes Bedford Borough, Central Bedfordshire, Luton and Milton Keynes. These are four very different places that are also diverse within themselves. These differences affect what local people need from their health and social care services.

BLMK has a combined population of 932,000 which is projected to grow to 1,081,000 by 2035 if recent trends continue. The number of people aged 85 and over is projected to double by 2035 and there will be higher than average growth of the number of adults aged 65 and over, and the number of children and young people aged 10-19 years old.

Luton is the most urban, most deprived and most ethnically diverse of the four locality areas; Bedford Borough and Milton Keynes are urban with significant ethnic minority communities and areas of deprivation as well as some rural areas; Central Bedfordshire is the most rural, least deprived and least diverse of the four areas. It does however have pockets of deprivation and around 30% of its residents use acute hospitals outside of the BLMK footprint.

There are also significant differences in demographics, ethnic diversity and deprivation within the footprint. Across the BLMK geography there are some significant variances in health and wellbeing outcomes. For example, healthy life expectancy at birth, an estimate of the average number of years lived in good health, varies from 61.3 years for men in Luton to 67.6 years for women in Central Bedfordshire.¹

¹Bedfordshire, Luton and Milton Keynes (BLMK) Single System Operating Plan 2019/2020 - 11th April 2019 version 1.0

Across the BLMK ICS footprint, NHS commissioners, providers and local authorities have committed to working in partnership on the priorities for their local plan.

Prior to the start of this project, local Healthwatch met with ICS colleagues to outline the engagement programme and to determine their priorities. Following discussion, it was agreed that in addition to seeking public views on general health and care services, local Healthwatch would also conduct focused engagement on cancer and mental health services as these are priority areas for BLMK ICS and also the NHS Long Term Plan. Whilst these are not the only commissioning priorities within the BLMK area, cancer and mental health services are two areas where performance against national constitutional standards needs to be improved and will continue to be a focus. This includes engaging with people who access those services. The feedback received from Healthwatch on these two service areas, as well as general health and care services, will be extremely valuable in informing and developing BLMK plans and future engagement activity.

Engagement work comprised, firstly, of two national surveys developed by Healthwatch England: on people’s general experiences of health and care services, and a condition specific survey. These surveys were used to gather people’s views on NHS services across the BLMK ICS footprint. The surveys were distributed locally, at targeted engagement sessions and completed online. Secondly, in agreement with our ICS leads, we held three focus groups in each of the four areas in BLMK: Bedford Borough, Central Bedfordshire, Luton and Milton Keynes.
One focus group was held with the general public to collect people’s views on ways to improve NHS services, to share their ideas on how people can live healthier lives and what improvements they think could be made to help people access services quickly. Two further focus groups concentrated on two specific conditions: one was held with cancer patients and/or relatives and carers, and one with mental health service users. People were asked to share their ideas on what they would change about the way the NHS in BLMK supports people with cancer and what should mental health support look like and what needs to change about what is currently available. A total of 12 focus groups were held across the BLMK area.

The programme of engagement ran for a six-week period, from mid-March to 30th April 2019. In total, local Healthwatch engaged with nearly 1000 people across BLMK - of which we had 801 responses via the survey and direct feedback from 160 people in a focus group setting - on their experiences and views of how health and social care services could be improved across BLMK.

Our aim was to give people across BLMK the opportunity to have their say on how the national plan is delivered locally. The views gathered will feed into the development of the NHS local plans.

**Key themes** were explored, as follows:

+ Prevention
+ Management - diagnosis & treatment
+ After Care - support

**Key research questions** - in addition to using the surveys to gather people’s views on NHS services across the BLMK ICS footprint by sharing online and in paper format at targeted engagement sessions, co-ordinating Healthwatch across BLMK used key research questions in the focus groups.

Healthwatch England’s focus group toolkit was used to explore the three key themes identified above asking key questions on people’s opinion of NHS and social care services. Questions for the general focus group included the following:

+ What has worked really well for them?
+ What do they feel has not worked well?
+ What must change to improve NHS services?
+ What matters most to them?
+ How and when do they wish to be engaged, and to feedback their opinion and views, on changes made to NHS service design and delivery?

**Questions for the condition specific focus groups** - cancer and mental health - included the key research questions identified above as well as more specific questions set by the BLMK ICS leads, as follows:

+ If you needed it, how easy did you find it to get information and support once your treatment had ended?
+ Do you have any specific views on how we could improve support for cancer survivors?
+ How can we involve you and your family in improving the mental health support that is available in our area?”

This report contains an analysis of feedback received from engagement with the public, patients, service users and carers from across BLMK. The report comprises an overview for the BLMK footprint as a whole, with key findings on general health and care services and the local priorities of cancer and mental health services, recommendations, next steps, methodology and acknowledgements. The Appendix can be found at the end of the report: Appendix A contains charts illustrating the demographic characteristics of the survey respondents for BLMK overall, and the four Healthwatch areas separately: Appendix B outlines the BLMK ICS engagement approach.

A separate report highlights the key findings for each of the constituent local Healthwatch areas: Bedford Borough, Central Bedfordshire, Luton and Milton Keynes.
Common themes from across all services throughout the entire BLMK area are highlighted in the key findings below. Individual, condition specific and ‘place’ based findings can be found later in the report.

### What works well for people in Bedfordshire, Luton and Milton Keynes?

- The range and quality of care available once it is accessed, and the many knowledgeable, responsive and caring staff;
- Community support from the voluntary sector - both national and local;
- The range of communication methods that are available: the ability for people to access their records, order repeat prescriptions and book appointments electronically, and apps for mental health services, as well as being able to have information on paper and make appointments by telephone.

### What could be better for people in Bedfordshire, Luton and Milton Keynes?

- Better access to services, both health and community, with support available 24/7 and not just during working hours for all services, with shorter waiting times, culturally appropriate services and more local provision;
- A more holistic and joined-up approach among health professionals - links between services are seen to be problematic;
- Improved information across a range of areas: basic health literacy is desperately lacking, which is impacting on people’s ability to make informed and supported decisions about their health and care; awareness of services is also lacking - people want better signposting to groups, networks and sources of information.
### In Focus

#### Cancer health and care services

<table>
<thead>
<tr>
<th>What works well?</th>
<th>What could be better?</th>
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<tbody>
<tr>
<td>- Treatment and care after diagnosis - this is particularly strong in Central Bedfordshire and Milton Keynes;</td>
<td>+ More health education, with campaigns not just focusing on screening, but providing other information, such as increases in survival and new treatments;</td>
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<td>- Compassionate and understanding nursing staff;</td>
<td>+ Screening not to be restricted by age;</td>
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<tr>
<td>- Information and support from local and national voluntary schemes and organisations, when these are accessed.</td>
<td>+ Better communication: improved, and more timely, throughout the cancer journey to help people make informed choices; raised awareness of the services that are available, both community and NHS.</td>
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#### Mental health services

<table>
<thead>
<tr>
<th>What works well?</th>
<th>What could be better?</th>
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<tr>
<td>- Access to online information and services - text reminders, online therapies and apps, and websites to find information without needing to speak to professionals in the early stages;</td>
<td>+ Better access to services and a more holistic approach - therapies that work in conjunction with each other and are delivered together would provide more comprehensive treatment, particularly for complex needs - with shorter waiting times, more long-term help and more recovery support in the community;</td>
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<tr>
<td>- Being offered therapy, particularly one-to-one counselling sessions.</td>
<td>+ More support in prevention and early intervention before people get into crisis, which could greatly improve quality of life outcomes - current mental health support seems to be aimed at more severe conditions;</td>
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<td></td>
<td>+ Better awareness - both in terms of signposting of services that do exist (networks, groups, counselling options, online services) and in the general population to continue to fight for social inclusion and reduce the stigma attached to mental ill health.</td>
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In Detail

What matters most for people in Bedfordshire, Luton and Milton Keynes?

Healthy life

Survey respondents in BLMK 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 45% choosing this option. Men were equally as likely as women to choose this statement. For people with a disability and members of the LGBTQ+ community, ‘professionals that listen to me when I speak to them about my concerns’ was the most important statement (42% and 39% respectively). However, they are all important to people. When people were asked to rate the importance of the statements in the chart, each one was rated important or very important by at least 93% of respondents.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Access to the help and treatment I need when I want it</td>
<td>45%</td>
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<tr>
<td>Professionals that listen to me when I speak to them about my concerns</td>
<td>24%</td>
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<tr>
<td>The knowledge to help me do what I can to prevent ill health</td>
<td>15%</td>
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<tr>
<td>Easy access to the information I need to help me make decisions about my health and care</td>
<td>12%</td>
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<tr>
<td>For every interaction with health and care services to count; my time is valued</td>
<td>48%</td>
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Suggestions for what more could be done to help people live a healthy life were centred around better and quicker access to professionals and services - particularly GPs, local services and mental health services. Survey respondents also saw a need for better communication to create a greater awareness of those services that do exist, and better access to information more generally on how to live a healthy and active life. There were also requests for access to groups and affordable fitness programmes or exercise facilities, particularly locally.

“Health screening should not be stopped because of age; we are all living longer.”
“Being able to access care when I need it - not making it so hard to see right person.”
“Easy access to healthy eating/exercise options - without having to join a commercial gym.”
“Display information clearly/provide contact information for groups and advice centres.”

What would you do?
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 BLMK in being able to manage and choose the support they needed. Almost half (48%) chose this option, with the proportion rising to 58% 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’) and the percentage rating each statement as important or very important are shown in the chart below. 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 96% for both ‘choosing the right treatment is a joint decision between me and the relevant health and care professional’ and ‘communications are timely’.

![Chart showing importance of statements]

- Choosing the right treatment is a joint decision between me and the relevant health and care professional: 70% very important, 26% important
- Communications are timely: 67% very important, 29% important
- I have time to consider my options and make the choices that are right for me: 54% very important, 40% important
- I should be offered care and support in other areas if my local area can’t see me in a timely way: 49% very important, 42% important
- My opinion on what is best for me, counts: 51% very important, 38% important
- I make the decision about where I will go to receive health and care support: 46% very important, 42% important
- I make the decision when I will receive health and care support: 39% very important, 42% important
- If I have a long term condition I decide how the NHS spends money on me: 37% very important, 37% important
Many focus group participants feel there is a need to improve access to services such as availability of GP appointments and more local provision of services. They 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.

The use of technology divided people. Several members of the focus groups want more effective use of IT for communication and like the online services that could be used to book appointments, order prescriptions and access their own records. However, some people, mainly the older generation, do not necessarily have access to computers, laptops or tablets, or feel comfortable using them, which could put them at a disadvantage; they want to be able to access services using their phone.

Survey responses echoed the call for easier and quicker access to services, particularly GPs. Respondents 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. A need for better access to advice, possibly through drop-in centres, was also highlighted. Other suggestions by survey respondents included: better communication (for example, being able to have discussions with professionals), a more holistic joined-up approach among health professionals with better communication between them and being more informed about options and outcomes.

“There is a lot they can do at my GP. My medication was reviewed by a pharmacist there and they were incredibly helpful.”

“The surgery is closed two afternoons a week; patients are queuing outside the surgery at 7.30am.”

“The online system for appointments is good. Perhaps more help can be given to those that are less digitally confident?”
Independence and staying healthy with ageing

People in BLMK attach a high importance to being able to stay in their own homes for as long as it is safe to do so when they get older. Overall this was deemed the most important of the five statements shown in the chart below: half (50%) chose this option compared with around 9%-14% for each of the other options. Men were more likely to choose this option than women (59% compared with 48%) and the proportion generally increased with age: 32% of under 18s said it was the most important, rising to 66% of those aged 65-74 and 61% of those aged 75 and over. Under 18s said that ‘I want my family and friends to have the knowledge to help and support me when needed’ was most important for them (34%). However, people attach a high importance to all the statements. When they were asked to rate the importance of each of these statements (on a five-point scale from ‘very important’ to ‘not important at all’), the proportion that said each statement was important or very important ranged from 85% to 95%.

When people were asked for suggestions about what would help them to retain their independence, affordable (or free) home care and practical support to enable them to stay living in their homes and community was high on the agenda. They want better care at home options, including more care in the community from specialist services, good district nurses, health and care providers to have a better awareness and understanding of their needs, and carers provided for basic help if required. Several responses were related to their family and friends – giving them support too and involving them in conversations. They also want to keep active and involved in the community to prevent social isolation - suggestions to enable them to do this include social groups (ideally free) and access to exercise classes. They also see transport to access services as being important and asked for more information on how to keep healthy.
“Social care! This is totally missing so I end up in hospital instead when I don’t need to be there.”

“Opportunity to socialise and stay active.”

“Little video clips on media could depict how some people manage to cope with relative ease. I think if people visually see someone who has age and debilities on their side and watch how they cope, more people would subconsciously follow and not just give up and think the NHS can do everything. Show how helping ourselves helps our situation.”
What did they tell Healthwatch?

Local engagement took place through 12 focus groups across BLMK, attended by 160 people in total and covering a wide age range from late teens to 90s. In addition, useful suggestions were also received through the free format questions on the survey. The narrative below expands on the highlights given on page 7 of this report.

What works well?

+ The range and quality of care available once it is accessed, such as the new mental health provision in primary care, and community care in some GPs’ surgeries. In particular, peoples’ experiences with cancer are that once they were through to a specialist, the treatment and support was thorough, efficient and timely. 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; walk-in centres are also seen to be useful. People are positive on the whole about the staff that they come into contact with.

+ Community support from the voluntary sector - both national and local. National high-profile organisations such as Macmillan, the British Heart Foundation and MIND provide valuable information, advice and support. Focus group participants have positive experiences of local groups, including the Good Neighbour Scheme that offers low level support. Voluntary transport was valued, not only for trips to the hospital/doctors but also pleasurable trips out in the community.

What could be better?

+ Getting access to services remains a high priority for everyone, with support available 24/7 and not just during working hours for all services. 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 services are available, with this lack of early intervention possibly leading to A&E attendance or crisis. People also want: more investment in mental health services; shorter waiting times for appointments with professionals; more choice on where they receive care with better local provision of services (including drop-ins); and improved social care (including home care, personalised care and continuity of care) to enable people to continue to live in their own homes.

+ A more holistic and joined-up approach among health professionals is needed, particularly when facing complex needs. Links between services are seen to be problematic and improved communication should be a priority, while continuity of professionals is also important. 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.
What works well?

+ People appreciate the range of communication methods that are available and many like the use of IT for speed and efficiency. The online system for appointments, prescriptions and accessing records 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, particularly 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 groups 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?

+ Communication across a range of areas is a third priority. Basic health literacy is lacking, which is impacting on people’s ability to make informed and supported decisions about their care, and to live healthily as they get older. Health education is not consistent. Awareness of services is also lacking: people want better signposting to groups, networks and sources of information. During the focus groups some 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 - for many this can be done electronically, but some, particularly the elderly, do not have access to technology.
Cancer health and care services
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. Four cancer focus groups were held across BLMK, with a total of 52 participants. Of the 245 people who completed the condition-specific survey, 62 respondents (32 women and 27 men) told us about cancer; they had an older age structure than participants to the survey as a whole.

Prevention and/or early intervention

People from the focus groups highlighted the importance of awareness campaigns. Many feel that high promotion campaigns work well and they were able to name awareness campaigns. However, they want even more health education, with campaigns not just focusing on screening, but providing other information, such as increases in survival and new treatments. They see preventative health care screening and early intervention as essential. Those in one of the groups with recent experience reported that the two-week pathway had been adhered to. Participants want the NHS to invest in less invasive screening, which they feel could increase uptake, and they do not want screening restricted by age. They also called for relevant training for all healthcare professionals.

Overall respondents to the survey had a mixed experience in accessing help and support. Just under half (47%) said that when they first tried to access help, the support they received met their needs and a further quarter (27%) said it somewhat met their needs. Those whose condition had started more than three years ago were almost twice as likely to say that support had met their needs than those with more recent experience (68% compared with 36%). However, it is hard to say whether this reflects changes in support or changes in expectations.

Assessment, diagnosis and treatment

After diagnosis, most focus group participants felt positive about their treatment and care, saying that it was a thorough and efficient process from diagnosis to treatment. This was supported by survey respondents, who were more than twice as likely to rate their overall experience of getting help as positive/very positive than negative/very negative (56% compared with 24%).

Members of the focus groups 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. 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.

People appreciate being given options and time to make their choices, but want improved, and more timely, communication (with ‘ordinary language’) throughout their cancer journey. A quarter (25%) of survey participants said that they didn’t get timely and consistent communication from all the services, and a further third (33%) said they only received it somewhat. People said they would like information about treatment/diagnosis to be told to them compassionately, and in person, by a consultant, with someone with them if they wanted; they suggested information about emotional support should be offered by a specialist nurse. Some 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.
Transport was an issue raised by some focus group and survey participants: they 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. Other suggestions included: better, more personalised, culturally-appropriate, co-ordinated treatment and support; a more holistic approach that takes into account physical and mental health; more choice on where people receive support and treatment, ideally closer to home; and more consideration for carers.

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. Overall, half (52%) of survey respondents said that the support options met their needs and a further 38% said they did somewhat. Focus group members gave examples of good initiatives (such as Hope course, Lymphedema Talk, Look Good Feel Better, and Living with Cancer Conference) and supportive organisations (such as Garden House Hospice, Good Neighbour Scheme, and Macmillan). People value the opportunity to have choice, particularly if they can use services that are local, but some feel that improvements are needed, including better training for GPs and follow-ups from GPs.

There was a general consensus among the focus groups that awareness should be raised of the services that are available, both community and NHS. Other suggestions included: more information on what to expect after treatment and how diet and exercise may help; counselling; and more support for families, friends and carers so they can be involved in the aftercare.

“Once I was in the door - the network if you will - all the specialist services worked well together from consultants, Macmillan nurses and care.”

“With other traumas such as rape or road accidents you are offered counselling, this should be part of the treatment offered to all those diagnosed with cancer.”

“People with cancer come from diverse backgrounds and this needs to be recognised.”

“I am pleased that cancer is, and should remain, a priority of the NHS.”
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.
Four mental health focus groups were held across BLMK, with a total of 56 participants. Of the 245
people who completed the condition-specific survey, 61 respondents (38 women and 19 men) told us
about mental health. Respondents to the survey who said they had a mental health condition tended
to be younger, and were more likely to be from the LGBTQ+ community, than respondents overall.

Prevention and/or early intervention

The consensus from the focus groups was that more support is needed in prevention and
early intervention, which could greatly improve quality of life outcomes. They feel that more, and
better, early intervention is needed at grass roots level as current mental health support tends to be
aimed more at severe conditions. The focus groups also highlighted the need for better promotion of
services that do exist before people get to crisis. Participants gave some examples of good practice
- Time to Change Campaigns, peer education, street triage service, Primary Care Plus in surgeries,
and calling helplines and 111 for support. Some members of the focus group had good experiences of
using websites to find information, without needing to speak to professionals in the early stages.
Nevertheless, on the whole they felt awareness needs to be raised in the general population, in the
workplace, and in schools. One suggestion was for all schools to have a qualified mental health
practitioner funded by the NHS. They stressed the importance of continuing to fight for social inclusion
and reduce the stigma attached to mental ill health.

Some people reported being seen quickly when at risk, while others had had negative experiences
with GPs who they felt needed mental health training. In addition, the Bedford focus group included
some hearing-impaired participants who were concerned that GP surgeries were not BSL friendly.
Mental health focus group members suggested that there should be dedicated mental health
professionals at GP surgeries and more training on mental health was needed for GPs. They also want
continuity of professionals, particularly in early conversations to build up trust, and better support
for people with multiple needs.

Many participants mentioned long waiting times from referral to appointments. This is supported by
the survey results. Three-fifths (58%) of respondents to the survey said that the time they had to wait
to receive their initial assessment or diagnosis was slow or very slow. A similar proportion (59%) said
that when they first tried to access support it did not meet their needs; only 15% said that it did.
Comments from survey respondents echoed those from the focus groups, with complaints about
unsupportive GPs, long wait times to see mental health practitioners and lack of continuity between
child and adult mental health services. They also wanted greater availability of sessions with mental
health practitioners.
Being offered therapy, particularly counselling, was highly valued by members of the focus groups. They shared examples of other good individual experiences including having a care co-ordinator, good individual GPs and counsellors, cluster support, CAMHS art therapy, Campbell Centre and perinatal mental health support. They also 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.

Focus group members feel that there are some good staff in all services, but others were not always considerate. 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.

Nearly all those attending the focus groups complained that waiting times for appointments with all professionals (GPs, mental health community care, general hospital services, counselling, talking therapies) were too long. The general view was that there needs to better access to services with shorter waiting times, and more collaboration between services. There was also concern about the transition process - between inpatient and outpatient services (which they felt was a step down), and between children and young people’s mental health services and adults (which they felt needed to overlap). Suggestions for improvement included: managing relationships more robustly through transitions; having access to support nearer people’s homes; more training in mental health for GPs and not just prescribing tablets; sessions to understand medication with the opportunity to ask questions; and information for parents/carers on how to support children/young adults while they are on waiting lists.
Respondents to the survey also told us about lack of support, some useful sessions that were too short, a lack of continuity in care, not enough counselling and that they felt there was overreliance on drugs. Two in five (39%) said that after being diagnosed they were not offered access to further health and care support. Those that had received support gave examples of being offered one to one counselling, and 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. Of those that answered the question about the time they had to wait between initial assessment/diagnoses and treatment, around half (54%) said it was slow/very slow, just 15% said it was fast/very fast.

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. They also wanted 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 services provision across geographical areas.

The experience of the people at the focus group suggests that aftercare needs more investment. Focus group participants had similar comments about ongoing care and support as they did for assessment diagnoses and treatment - some have experience of good GP surgeries while others feel that high staff turnover means that there is no relationship with support workers and lack of support. MIND, Rethink and Carers MK are seen to provide good ongoing support and people are positive about courses such as IMPACT - run By Path2Recovery; support from family and friends, as well as acquaintances they had made on their mental health journey, is also valued.

There were many suggestions for improvement including a need for better signposting to networks and groups, perhaps in the form of an online service users’ directory, 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. It is well known that staff turnover can be high in mental health services and participants felt that a handover, where possible, would make the transition easier for people. People also want more help to understand the progression of their care, more long-term help, more recovery support in the community (for example, a recovery hub with social drop-ins, crisis house, café and local help line), more deaf awareness and an up-to-date and holistic approach to recovery with alternative therapies, upskilling, fitness and nutritional information. One person suggested a social inclusion service, like the Maudsley Trust.

Results from the survey also highlight the difficulties in accessing ongoing support and information. Half (54%) of respondents said that they had not received timely and consistent communication from all the services that they came into contact with. Aspects that the respondents felt worked well included art therapy, counselling (but not enough sessions) and group sessions. A third (35%) of respondents to the survey said that they needed the NHS to supply a lot of support to help them stay healthy, and a further half (52%) wanted some support. Of the 27 people in the survey who had multiple conditions, 59% said that this made it harder for them when seeking support.
‘GP didn’t understand and, when eventually referred to CAMHS, my son wasn’t offered the therapy he needed because he was within 6 months of his 18th birthday when he would have to transfer to adult mental health services. When he did transfer there was no help available and 7 years on he has received only a short course of therapy. Although seen by a specialist centre outside Milton Keynes which made detailed recommendations, we are told that there is no resource available to deliver on these recommendations. In comparison to acute services and the cost of treatment for physical illnesses such as cancer, the therapy required is relatively low cost and could make a huge difference to his life. As it is, he is unable to work and live the life that could be attainable for him. Words cannot describe the huge sadness and frustration I feel at the appalling way this has been handled.’

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 36% of people who answered the question - followed by ‘I can make appointments online and my options are not limited’ (16%) and ‘I have absolute confidence that my personal data is managed and well kept” (15%). However, young people under 18 chose this latter option as the most important - a third did so.

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 the proportion rating each statement as important or very important are shown in the chart below. It shows that all of these statements are important to people. Each statement in the chart below was rated important or very important by at least two-thirds of those who responded. This ranged from 92% rating ‘any results are communicated to me quickly making best use of technology’ as important/very important, to 66% for ‘I am able to talk to other people who are experiencing similar challenges to me’.

What is most important when interacting with the NHS?

- Any results are communicated to me quickly making best use of technology: 60% very important, 32% important
- I have absolute confidence that my personal data is managed well and kept secure: 55% very important, 28% important
- I can talk to my doctor or other health care professional wherever I am: 53% very important, 32% important
- I can access services using my phone or computer: 49% very important, 35% important
- I can make appointments online and my options are not limited: 51% very important, 30% important
- I manage my own personal records so that I can receive continuity in care: 40% very important, 33% important
- I am able to talk to other people who are experiencing similar challenges to me to help me feel better: 31% very important, 35% important
**What works well?**

- Once people see a specialist then care is generally good and timely, particularly for cancer patients, as discussed earlier.
- The staff people come into contact with are generally knowledgeable, responsive and caring and good at explaining treatment.
- There are some very good individual GP surgeries and walk-in centres are a useful resource.
- The ability for people to access their records, order repeat prescriptions and book appointments electronically, and apps for mental health services.

**What could be better?**

- Improved access to health professionals, including direct access to consultants, health care professionals holding clinics at local surgeries, the ability to discuss options and consequences for care and support, GPs with extended opening hours, being able to talk to the GP on the phone and the ability to make timely appointments.
- A more holistic joined-up approach among health professionals, with improved communication between departments, so separate but potentially connected health issues can be understood together.
- Better access to mental health services.
- 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 12 focus groups held across BLMK used key research questions on people’s opinion of NHS and social care services. The responses to the question ‘How and when do they wish to be engaged, and to feedback their opinion and views, on changes made to NHS service design and delivery’ are summarised below.

When?

+ Answers ranged widely about how often people wanted to be consulted. Many wanted consultation throughout the process, others suggested periodically, and some wanted annual local reviews.

How?

+ Focus group members were clear that engagement should be with 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. They suggested making use of groups such as PPGs and national organisations (for example, Macmillan) to draw together people to be involved in the engagement process and to access seldom heard groups by going to them (for example, supermarkets).

+ A more creative approach could be used - 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).

+ Any engagement events should be accessible, for example on public transport routes, have expenses paid, and with some engagement outside working hours.

+ The process should be humanised. Feedback should provide the opportunity to give experiences and opinions - not just a tick box. Engagement should be done in a range of ways, not just online as this would leave out certain segments of society.

+ Feedback following engagement is vital, so people know the information they have provided has made a difference - case studies are important, not just statistics. Updates need to be provided on what is being done, and what isn’t, and the reasons for it.

+ A youth mental health partnership board.

+ Representatives should join local meetings to engage with local people. Commissioners could attend the Working Together group to actively get service users and carers perspectives and views.

+ People wanted to give feedback to impartial independent bodies, such as Healthwatch, trained and accredited people, or directly to commissioners.
A young person’s view

In the timescales given to complete the engagement work, it was difficult to gather young people’s views across BLMK, despite all local Healthwatch including young people and the seldom heard in the distribution of the surveys and the opportunity to take part in the focus groups. We would have liked to hear directly from them and given more time would have organised suitable engagement sessions. However, we did speak with some young people and one young person told us:

‘I would like to improve the health services for people with disabilities and see more health care professionals involve the patients, not assuming the patient lacks mental capacity.

If somebody has a learning disability, they are not stupid, they just struggle sometimes. If you take the time to involve them in their care and explain things to a level that they understand, they will be more positive about treatment as they will actually understand what is happening.’
Recommendations

Many people contributed to this engagement programme, sharing their experiences and giving their views on how they feel health and social care services could be improved across BLMK. Consideration of public feedback to inform change and improve the quality of services for patients and the public is essential and as such Healthwatch from Bedford Borough, Central Bedfordshire, Luton and Milton Keynes have included recommendations to be considered by the BLMK ICS when developing their Plan. These recommendations have significance across cancer, mental health and general health and care services.

Our recommendations include the following:

+ The feedback given in this report representing the ‘voice’ of local people, across BLMK, is clearly visible in future commissioning decisions and in pathway redesign.
+ Local Healthwatch across BLMK are commissioned by BLMK ICS to undertake more engagement with the public, as the BLMK plan is developed, over an agreed and feasible timescale.
+ BLMK ICS develop a plan that can demonstrate improved access to services (outside of normal working hours), with shorter waiting times and an increase in local provision.
+ Healthcare professionals to give more consideration to a holistic and joined up approach to care and treatment, not just through changes to digital communications which may take time to implement, but through taking actions now for the benefit of their patients.
+ Patient information and advice about all services should be mapped and revised to be more visually engaging and considered in presentation, with due consideration to ‘Accessible Information Standards’, for both written and electronic information, and the BLMK plan to reflect the need to vastly improve signposting services to prevent patients from bouncing, and falling, between services.
+ The BLMK ICS to urgently review their screening processes and eligibility criteria - we are all living longer and age restrictions for screening processes should be revised for certain conditions. Also, expand health education campaigns, so it’s not just about screening but survival rates and new treatments.
+ BMLK plan to clearly demonstrate how provision of early intervention and prevention support will be increased for people with mental health conditions to prevent many people escalating into crisis; to see a clear increased investment in prevention and parity of delivery between crisis and prevention services.
The ICS response to our recommendations:

+ The Engagement work local Healthwatch across BLMK has done is integral to the development of an engagement approach and ensuring the BLMK ICS response to the NHS Long Term Plan (see attached presentation at Appendix B) reflects the views of local people. Our aim is for the BLMK Plan to 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. The ICS has reviewed the feedback from the local Healthwatch report, and the outcomes of the engagement activity undertaken across BLMK over the past two years. This gap analysis has also been triangulated with work undertaken by planning leads, in each of the four places, to understand local priorities. This has highlighted where the gaps are for undertaking targeted engagement to inform the BLMK Plan.

+ We welcome the findings from the Healthwatch engagement which helpfully reinforced that many of the priorities that we have identified and are working on e.g. better access to services and support 24/7; more integrated and personalised care, particularly for people with multiple/ complex medical conditions; broader and improved communications and an increased focus on prevention/ early intervention, are the things local people would like to see improved. The Healthwatch report is a reminder of what we need to plan services/ pathways from a patient perspective and presents an opportunity to continue to focus on making improvements. One area we will be looking at closely is better communication and signposting which was a key theme throughout.

+ The BLMK ICS have plans to investigate particular elements of the local Healthwatch report further, however, as previously stated, we will look at the gaps highlighted and will also take what we have learned from the local comprehensive Healthwatch report and will consider this alongside our local priorities. Based on this we will determine activity and the further engagement to be undertaken.

+ Screening criteria are set nationally by UK National Screening Committee who do an extensive review of the evidence in determining which cancers to screen for, the frequency of screening and the age it should apply to. You can read more about the process here: 
  
  https://phescreening.blog.gov.uk/2019/05/07/making-sure-the-uk-nsc-keeps-recommendations-up-to-date/

  BLMK does not have the resources or expertise to replicate this process. We are not screening as many of those who are eligible as we would like, and that must be our focus.

+ The timeline for producing the ICS local plan is detailed in the attached presentation (see Appendix B).

+ BLMK ICS will be using the local Healthwatch NHS Long Term Plan engagement programme to set the standard for ongoing engagement with our population (Scale) and with our communities (Place). We will use our existing governance structure which includes local forums and committees, patient and public representation and Healthwatch, to track progress against the plan. We will also be involving local Health Overview and Scrutiny Committees (HOSC) and, where appropriate, the BLMK Joint Health Overview and Scrutiny Committees (JHOSC).
The findings in the local Healthwatch report will be discussed at the following:

- BLMK ICS Chief Executive Group (key leadership forum for BLMK)
- BLMK ICS Planning Group
- BLMK ICS Communications Collaborative (which oversees the engagement plan development and delivery)
- Three Patient groups - BCCG / LCCG / MKCCG
- Governing Body Meetings - BCCG / LCCG / MKCCG
- BLMK Joint Health Overview & Scrutiny Committee (JHOSC)

All of the above, collectively, will be responsible for developing the BLMK Plan and will take into account the findings from Healthwatch to inform the Plan.
NHS England and NHS Improvement funded the Healthwatch network to carry out engagement with communities across the country to establish how the Long Term Plan (LTP) should be implemented locally. This report contains an analysis of feedback received from engagement with the public, patients, service users and carers from across Bedfordshire, Luton and Milton Keynes (BLMK). Upon publication, the report will be shared with NHSE and NHSI to enable them to use our findings from the report to inform their BMLK Plan.

Prior to publication of the report, Healthwatch Central Bedfordshire (HWCB), as the coordinating Healthwatch for the NHS LTP Engagement Programme across Bedfordshire, Luton and Milton Keynes (BLMK), presented some early findings of public feedback from initial evidence gathered, to key stakeholders and the public, including our ICS colleagues, in May 2019 at a Discovery Day organised by BLMK partners. The Discovery Day was designed to engage with local communities to ensure that the BMLK plan is shaped and informed by those living across BLMK; understanding what matters to local people and how services might be improved.

Following this event, HWCB presented a copy of the initial draft report to our ICS colleagues to establish where and how they will be using the insight provided and how this is influencing decisions.

Undertaking this programme of engagement, across BLMK, enabled each local Healthwatch to work in collaboration, and coordinate our activities, to deliver high quality standardised data. Clear guidance from Healthwatch England assisted in focussing our work programme which allowed a rich variety of valuable feedback from the public, patients, service users and carers. Using a structured approach and giving local residents the opportunity to complete a survey, and to participate in active feedback sessions, ensured that people felt listened to and valued.

All local Healthwatch, with support from partner organisations and our volunteers, were able to reach individuals and groups we may not have previously engaged with which helped to further raise our reputation as a key stakeholder in the local health and social care community.

Healthwatch across BLMK will continue to engage with the public as local plans are refined and implemented via patient / service user forums, groups and events. We will actively use the feedback gathered to drive change and influence commissioning decisions, working jointly with our ICS partners to establish follow-up sessions (with focus group participants and key partners) to ensure co-production and continuous effective involvement with the public at all stages of the implementation of the NHS Long Term Plan. Each local Healthwatch will also use the feedback gathered to inform future work projects, explore areas that are priorities within BLMK, and focus on particular areas such as mental health and cancer services.

Finally, upon publication of the report, each local Healthwatch will share with its Board Directors and Trustees, Advisory Panels, key partners and stakeholders, including Health and Wellbeing Boards, Overview & Scrutiny Committees and Governing Bodies, to support the development of annual work programmes, linking in with national and local themes that feed into our work.

We will use the evidence highlighted in the report to inform related activities and projects, and use the insight gathered to monitor evidence of the patient voice being acted upon, in the design and delivery of future health and social care services across Bedfordshire, Luton and Milton Keynes, as local plans are shaped and developed.
The local research plan provides a high-level overview of the approach to engagement and involvement in local conversations about the NHS Long Term Plan with local Healthwatch across the Beds, Luton, and Milton Keynes (BLMK) Integrated Care System.

**Objectives**

**Long Term Plan Programme Objectives:**

+ Promote and enable the completion of the Long-Term Plan survey(s), (General and Condition-Specific), aiming for at least 250 respondents per survey from each Healthwatch area in BLMK - a total of 1000 responses.
+ Analyse the results and include in a report for the relevant ICS.
+ Identify and summarise existing insight and evidence that is relevant for the Local Plan.
+ Carry out at least three public engagement events or focus groups involving a minimum of ten participants in each area of BLMK: one with the general public, one focusing on cancer and one focusing on mental health. Themes and topics have been agreed locally with the BLMK ICS and co-ordinating Healthwatch to reflect local needs, using Healthwatch England’s focus group toolkit. A total of 12 focus groups will take place across the BLMK area.
+ Carry out any other reasonable activities collectively agreed with the BLMK ICS and co-ordinating Healthwatch.
+ Meet and work in partnership with other local Healthwatch in the BLMK ICS area during the engagement period.
+ Assist in monthly reporting to Healthwatch England and the BLMK ICS.
+ Support the co-ordinating Healthwatch to analyse data, insight and findings by providing them in an agreed format, utilising tools provided by Healthwatch England.

**Local Objectives:**

Our aim is to give people across Beds, Luton and Milton Keynes the opportunity to have their say on how the national plan is delivered locally. The views gathered will feed into the development of the NHS local plans. Key themes will be explored, as follows:

+ Prevention
+ Management - diagnosis and treatment
+ Aftercare - support
Engagement activities encompassed all three theme areas through two HW England’s surveys: on people’s general experiences of health and care services, and a condition specific survey, focusing on cancer, heart and lung diseases, mental health, dementia, learning disability, autism and long-term conditions, e.g. diabetes and arthritis. These surveys were used to gather people’s views on NHS services across the BLMK ICS footprint by sharing online and in paper format at targeted engagement sessions.

**Key Research Questions:** In addition to using the surveys to gather people’s views on NHS services across the BLMK ICS footprint by sharing online and in paper format at targeted engagement sessions, co-ordinating Healthwatch across BLMK used key research questions in the focus groups.

Healthwatch England’s focus group toolkit was used to explore the three key themes identified above asking key questions on people’s opinion of NHS and social care services.

**Questions for the general focus group included the following:**

+ What has worked really well for them?
+ What do they feel has not worked well?
+ What must change to improve NHS services?
+ What matters most to them?
+ How and when do they wish to be engaged, and to feedback their opinion and views, on changes made to NHS service design and delivery?

**Questions for the condition specific focus groups - cancer, and mental health - included the key research questions identified above as well as more specific questions set by the BLMK ICS leads, as follows:**

+ If you needed it, how easy did you find it to get information and support once your treatment had ended?
+ Do you have any specific views on how we could improve support for cancer survivors?
+ How can we involve you and your family in improving the mental health support that is available in our area?

**Limitations:** The approach to engagement focussed on the agreed theme areas - these were agreed by local Healthwatch and the BLMK ICS. The number of respondents to the surveys, particular for individual Healthwatch areas, did not always allow detailed statistical analysis and so only limited conclusions can be drawn around inequalities. In addition, the timeframe for the analysis was shortened due to the closing date for the survey being extended, while the publication date was not constraining the time available for analysis.
Within the tight timescales given for this engagement, we anticipated a lower response to both surveys and attendance at the focus groups than we normally would for this type of activity. As a consequence it was a challenge to analyse the sometimes small number of respondents to the surveys and focus groups across BLMK, however the analysis fully reflects both the quantitative and qualitative data collected.

**Focus group approach:** The focus group process allowed more flexibility in capturing people’s views and in BLMK, in agreement with our ICS leads, we held three focus groups in each area. One focus group was held with the general public to collect people’s views on ways to improve NHS services and two further focus groups concentrated on two specific conditions: one was held with cancer patients and/or relatives and carers, and one with mental health service users. A total of 12 focus groups were held across the area.

The data gathered from these processes provided snapshots of experience and expectations from the general public and from a relatively small number of patients affected by a specific condition: cancer and mental health. In addition to the agreed theme areas, as detailed above, questions covered workforce, digital solutions, primary care and the role of the community. The feedback provides a retrospective about how people feel about their previous or current treatment with some suggestions and views as to how patient journeys within the two areas specified, cancer and mental health, can be improved.

The following table shows the attendance at each of the focus groups. In total, 12 focus groups were held with 160 participants across the area; this more than achieves the minimum number of 120 participants aimed for in the local research plan.

<table>
<thead>
<tr>
<th></th>
<th>Date of group</th>
<th>Number attending</th>
<th>Age range</th>
<th>Male:female ratio</th>
</tr>
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<tbody>
<tr>
<td><strong>Bedford Borough</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>28/03/2019</td>
<td>10</td>
<td>18-75</td>
<td>1:9</td>
</tr>
<tr>
<td>Cancer</td>
<td>23/04/2019</td>
<td>8</td>
<td>50-90</td>
<td>8:0</td>
</tr>
<tr>
<td>Mental health</td>
<td>27/04/2019</td>
<td>15</td>
<td>18-75</td>
<td>1:4</td>
</tr>
<tr>
<td><strong>Central Bedfordshire</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>28/03/2019</td>
<td>16</td>
<td>Mid 30s-83</td>
<td>2:5</td>
</tr>
<tr>
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<td>09/04/2019</td>
<td>11</td>
<td>40-85</td>
<td>6:5</td>
</tr>
<tr>
<td>Mental health</td>
<td>26/04/2019</td>
<td>17</td>
<td>Mid 20s-mid 80s</td>
<td>7:17</td>
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<tr>
<td><strong>Luton</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>29/04/2019</td>
<td>15</td>
<td>36-83</td>
<td>1:4</td>
</tr>
<tr>
<td>Cancer</td>
<td>30/04/2019</td>
<td>17</td>
<td>29-83</td>
<td>6:11</td>
</tr>
<tr>
<td>Mental health</td>
<td>30/04/2019</td>
<td>14</td>
<td>25-83</td>
<td>5:9</td>
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<tr>
<td><strong>Milton Keynes</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>26/03/2019</td>
<td>11</td>
<td>30-65</td>
<td>3:8</td>
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<tr>
<td>Cancer</td>
<td>05/04/2019</td>
<td>16</td>
<td>25-75</td>
<td>5:11</td>
</tr>
<tr>
<td>Mental health</td>
<td>12/04/2019</td>
<td>10</td>
<td>18-65</td>
<td>1:1</td>
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<tr>
<td><strong>BLMK Total</strong></td>
<td></td>
<td></td>
<td></td>
<td>160</td>
</tr>
</tbody>
</table>

What would you do?
The following table details the number of survey responses that have been used in the analysis.

<table>
<thead>
<tr>
<th>Area</th>
<th>General Survey</th>
<th>Condition Survey</th>
<th>All</th>
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</thead>
<tbody>
<tr>
<td>Bedford Borough</td>
<td>176</td>
<td>73</td>
<td>249</td>
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<tr>
<td>Central Bedfordshire</td>
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<td>219</td>
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<tr>
<td>Luton</td>
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<td>69</td>
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</tr>
<tr>
<td>Milton Keynes</td>
<td>122</td>
<td>40</td>
<td>162</td>
</tr>
<tr>
<td><strong>BLMK Total</strong></td>
<td><strong>556</strong></td>
<td><strong>245</strong></td>
<td><strong>801</strong></td>
</tr>
</tbody>
</table>

**Timeframe**

*Surveys:* It was intended that the surveys would be launched at the beginning of March 2019 and close at the end of April 2019. The survey was launched in early March but did not close at the end of April as some areas were running behind schedule. It finally closed on 17 May 2019.

**Method**

*Engagement method:* The surveys, developed by HW England, have been shared with BLMK ICS and all key stakeholders across the BLMK area, including voluntary, community and social groups to maximise exposure and to encourage as many people as possible to engage and complete.

Local Healthwatch identified groups and organisations to engage directly to have conversations about the NHS Long Term Plan, and inform and provide participants for the focus groups.

Local Healthwatch aimed to attract a broad demographic to the focus groups, e.g., older people, younger people, carers, people with long term conditions, LGBTQ representation, people with sensory impairment and those accessing mental health services.

*Data Management:* The surveys, developed by HW England were hosted online. Each local Healthwatch that carried out local engagement using paper versions of the survey was to input data directly into the survey online. There were alternative methods of logging responses, provided by HWE, which were particularly used by Bedford Borough. The survey does not ask or require personally identifiable data - no names, addresses or contact information are required.

Feedback gathered from each participant taking part in the focus groups was anonymous - again, no names, addresses or contact information were used in the data analysis. However, any participants wanting to share their story more widely and willing to share their contact details would be followed up at the time ensuring that appropriate consent was acquired.

Data is kept electronically by each local Healthwatch and password protected. When sending to HWCB, as the local co-ordinator, for data analysis, the password will be shared separately for access. Co-ordinating Healthwatch will agree a timeframe for retention of data.

*Risk Assessment:* Each local Healthwatch undertook an appropriate risk assessment for each engagement activity conducted directly with local residents (focus groups). Specific considerations were given to particular groups of people, for example, those with a physical or learning disability, those accessing mental health services etc, as suggested by Healthwatch England in the Focus Group guides. This included disability access, culturally appropriate dietary requirements, easy read versions of literature etc.

*Ethical Considerations:* Each local Healthwatch is mindful of ethical considerations when undertaking engagement activities.
Consent: Healthwatch England’s survey(s) starts with an initial question confirming that people are happy for their responses to be shared with local Healthwatch.

Who was engaged: Local Healthwatch across BLMK engaged widely with the general public in each area, via publishing a link to the surveys on each local Healthwatch website, direct email to all key stakeholders, issuing a press release to local news outlets and contact with local radio stations plus promotion at local engagement events as part of current activities, which included face to face contact, telephone conversations, meetings and groups. A total of 801 responses to the survey(s) were received across the BLMK area.

Resources and collaboration
Skills and Expertise: Each local Healthwatch utilised the skills and expertise of its staff team. Each local Healthwatch has carried out engagement and involvement work previously which was also used to feed into the development of the NHS local Plans.

Technical: Surveys were mainly completed online, with all responses going direct to Healthwatch England. The raw data was sent in password protected excel spreadsheets to the co-ordinating Healthwatch (Central Bedfordshire) for analysis. Paper survey responses collected in Bedford Borough were directly input into an excel spreadsheet.

Roles and Relationships: Each local Healthwatch in BLMK agreed to work collaboratively on this piece of work. The content, style and approach for engagement around the NHS Long Term Plan was agreed by all partners. Healthwatch Central Bedfordshire were the Co-ordinating Healthwatch for this piece of work and liaised and communicated with local Healthwatch and the ICS Engagement Leads.

Quality assurance
Quality assurance processes will be in line with those outlined by Healthwatch England.

Conflict of interest
There has not been an identified conflict of interest in relation to this piece of work.

Intellectual property rights and publishing
All intellectual property rights in documents directly or indirectly made available by HWE to each Local Healthwatch pursuant to the Grant Agreement vests in HWE absolutely and exclusively unless otherwise specified and agreed.

Each Local Healthwatch agrees to provide a copy of all materials to provide HWE with the intelligence and insight it needs to enable it to perform effectively under the terms of the Health and Social Care Act 2012.

Audience: The audience for the outcomes of this piece of work will be local people and populations across the BLMK area, the ICS and its partners and local stakeholders.

Evaluation
Once the work has been completed and the report written and presented to all key stakeholders, there will be on-going discussion and conversations with the BLMK ICS about how local people’s views and opinions will be reflected in the ICS response to the Long-Term Plan and local implementation and delivery plans.
Acknowledgements

This programme of engagement involved a large amount of work, commitment and dedication; however implementation would not have been possible without the support of many individuals and organisations across Bedfordshire, Luton and Milton Keynes.

We would therefore like to extend our sincere gratitude to the many local residents across Central Bedfordshire, Bedford Borough, Luton and Milton Keynes, including patients, service users and carers, and their family and friends, who took the time to complete the NHS Long Term Plan Survey, either on line or in person, and to all the people who took part in a local focus group sharing their lived experiences, and providing feedback on a range of health and social care services, including cancer and mental health.

We are also thankful to Healthwatch England for their technical support and necessary guidance in implementing this programme of engagement.

In addition we would like to thank our ICS partners who supported and contributed to this programme of engagement and the many individuals, key organisations, voluntary, community and social groups, in particular those listed below, who gave their time and resources to help promote awareness of the project and encouraged their local residents to be involved and to have their say.

+ Access Bedford
+ ACCM UK
+ Bedford Borough Parent Carer Forum
+ Bedford Borough Parish & Town Clerks
+ Bedford College Deaf Community
+ Bedford Council of Faiths (Inter Faith Network)
+ Bedford Hospital
+ Bedford Maternity Voices
+ Bedfordshire Doulas
+ Bedfordshire Neuro Network
+ Bedfordshire Police
+ Bedfordshire PPG’s
+ Beds Prostate Cancer Support Group
+ Bosom Pals
+ CAMHS
+ Carers in Bedfordshire
+ CHUMS
+ Dunstable College
+ East London Foundation Trust
+ East of England Ambulance Service NHS Trust
+ Energising Positive Change
+ Flitwick Football Club
+ Groundwork LGBTQ Group
+ Hear Me Out
+ HWCB Young Healthwatch
+ i-learn
+ Little Eagles
+ Local Faith Communities & Community Leaders
+ Luton & Dunstable Hospital
+ Macmillan
+ Milton Keynes University Hospital NHS Foundation Trust
+ Mind BLMK
+ Mindful Table Tennis
+ Minds2gether
+ MK Cancer Patient Partnership
+ MS Society Bedfordshire
+ NHS Retirement Fellowship
+ Parkinsons UK Bedford
+ Paul Maclean (facilitator MK focus groups)
+ Probus
+ Q Youth
+ Rethink
+ Retirement Education Centre
+ Royal British Legion
+ St Thomas More Catholic Secondary School
+ The Primrose Unit, Bedford Hospital NHS Trust
+ University of the Third Age
+ Young Minds
+ Youthscape

Finally we would like to thank the Clinical Commissioning Groups in Bedfordshire, Luton and Milton Keynes for their support in sharing and promoting the survey and focus groups, and the local authorities across BLMK; Central Bedfordshire Council, Bedford Borough Council, Luton Council and Milton Keynes Council for their continued support of Healthwatch projects and activities.
Appendix A: Demographic characteristics of survey respondents
General Survey - BLMK - 556 responses [blanks are excluded from all charts]

General Survey - Age (BLMK)

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

General Survey - Sexual orientation (BLMK)

- Heterosexual
- I'd prefer not to say
- Gay or lesbian
- Bisexual
- Pansexual
- Asexual
- Other

General Survey - Ethnic group (BLMK)

- White British
- Gypsy or Irish Traveller
- Any other white
- Any other mixed
- Asian British
- Indian
- Pakistani
- Bangladeshi
- Black British
- African
- Caribbean
- Arab
- Other

What would you do?
What would you do?
Specific Conditions Survey - BLMK - 245 responses [blanks are excluded from all]

**Condition Survey - Type of condition (BLMK)**

- Cancer
- Mental health
- Long-term condition e.g. diabetes, arthritis
- Heart and lung diseases
- Learning disability
- Dementia
- Autism

**Condition Survey - Age (BLMK)**

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

**Condition Survey - Ethnic group (BLMK)**

- White British
- Asian British
- Black British
- Bangladeshi
- Any other white background
- African
- Indian
- Caribbean
- Any other mixed background
- Pakistani
- Arab
- Other

What would you do?
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.

We will engage at place on priority areas. Local plans will be developed/owned by ICS partners and delivered using local teams/networks.

**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 work with existing forums and networks to co-design our local plans that will inform the wider BLMK response.

Examples of forums

- Patient reference groups
- Health and Wellbeing Boards/OSC
- Healthwatch
- BLMK ICS Partners
- Vol org groups
- BLMK Staff
- Stakeholder advisory group
- Elected representatives
- Targeted audiences

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

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.

- What do we want for the future?
- Voluntary/Community organisations
- How do we respond to wider issues e.g., loneliness
- Clinicians/subject matter experts
- Commissioner/Providers/Local Authority
- Co-design of service
- Local people
- What matters to me?
- What does it mean to have good quality care?
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.

Timeline

- May: Discovery event with BLMK staff and stakeholders
- June: Healthwatch report published
- June to August: A draft engagement approach/outline plan
- Targeted conversations in each of the four places on agreed local priorities
- Co-design of engagement plan
- Summary of last two years BLMK engagement
- Plan assured by CCG patient forums/IHOSC
- Engagement continues throughout delivery of BLMK LTP
- Feedback to stakeholder group
- Partner organisations review draft
- Feedback to CCG patient forums/IHOSC
- Public/generic engagement in each of the four places (shopping centres)
- BLMK plan submitted to regional NHSE
- What we’ve heard summary
- For general information and to feed into ICS Priority Workstream/BLMK plans
- Partner organisations approve plan
- BLMK plan published
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