

Listening to our communities on our draft priorities: analysis of text feedback

Introduction

An engagement process was launched on 3 October to invite feedback from colleagues, partners and the wider community on the six draft priorities proposed by the Lancashire and South Cumbria Integrated Care Partnership (ICP).

The survey was open for a four-week period with an initial summary given after three weeks and a final summary of findings from the closed question options provided on 31 October. This included a summary of the Healthwatch focus group sessions undertaken over the same period.

Due to tight timescales the summary of findings did not include an analysis of the open text feedback responses that were received. Two questions were asked that required written responses. Between them these elicited 824 open text comments, consisting of over 23,000 words of text.

Analysis of open text responses

The findings will be considered in the order the survey questions were asked.

Is there anything else you would like to add regarding the proposed priorities?

Response levels

334 (45.6% of all survey respondents) provided a response to this question.

Of these, 174 (52%) indicated, in response to other questions in the survey, that they did not work for one of the organisations in the Partnership. Only a small proportion of these respondents (5%) identified which organisation they worked for and some of these were in fact, members of the Partnership. This seems to indicate that work remains to inform groups and individuals on the scope and membership of the ICP.

160 (48%) of respondents who provided additional comments indicated they worked for one of the member organisations. On balance therefore, approximately half of the comments provided were from members of the ICP.

In respect of organisational breakdown, of those providing a response to this question:

- 21 (6.2%) were from local government
- 105 (31.4%) were from the NHS

- 7 (2.1%) were from hospices
- 3 (0.9%) were from universities
- 24 (7.2%) were from VCFSE organisations
- 1 was from Healthwatch
- 167 (50%) were from no organisation or in a non-ICP organisation
- 6 left this element blank

In terms of ICP membership therefore, most responses came from NHS partners. From within the NHS the highest proportion of comments received were from NHS Trust staff, with 65, 19% of all those who provided their feedback to this question.

Themes

There was a broad range of issues and concerns that respondents raised. To make these more manageable some broad themes have been identified, split into two categories. The first relates to the main themes raised, where more than 5% of respondents mentioned the theme/issue in their response, and the second to those where fewer than 5% of respondents mentioned the theme but enough to make the issue resonate.

The main themes were, in descending order:

- Maternity, early years, or family related issues (46 – 13.8% of responses)
- Communication, co-ordination and collaborative working between partners and organisations and/or with communities (40 – 12% of responses)
- That it was hard to rank priorities or pick a single priority as they are all interlinked or all important (33 – 9.9% of responses)
- No comment or nothing further to add (30 – 9% of responses)
- Had an issue with the survey itself or about the priorities chosen (21 – 6.3% of responses)

Other, less frequently raised themes included:

- Access to services, especially GP services
- Workforce issues
- Older people services and/or social care investment and standards
- Mental health, LD, autism, loneliness/isolation
- Transport and/or keeping services local
- Cost of living, poverty
- Prevention
- Health inequalities
- Employment
- Palliative/end of life care
- Rural deprivation or disparity of service provision
- Housing, both social housing and new builds

Some of these less frequently raised themes are inter-linked or have an underlying connection and have been grouped together in a more detailed exploration of these themes below.

Maternity, early years or family related issues

This attracted the largest number of written responses and the comments received around maternity, early years and/or family issues related to the priority “starting well: supporting children and their families in the first 1000 days of a child’s life.”

Some of the comments received related to maternity care and support for pregnancy, touching on perinatal mental health, post-partum care, particularly around physiotherapy, fully staffed maternity units and support for pregnant mothers in more deprived areas. There was also a call for the continued emotional support in NICU units for parents who lose a child and for those whose children are born early.

Others were strident in the call for improved support services for young families, especially the need to invest in and restore the health visitor and school nurse service, which “have been run into the ground since they were taken over by Virgin and now HCRG.” It was felt that these services, and midwifery too, were vital to support families in the first 1000 days of life, with one respondent emphasising the vital role of breastfeeding and that “we don’t have the same support that we used to, families are very much alone.”

In addition, a proportion of respondents also called for the return of Sure Start centres. “I have witnessed a significant negative impact in deprived communities with the closing of Sure Start Centres. These were often lifelines for those with young children to help them get the best start in life.”

A significant proportion of those giving feedback on this priority however, felt the priority needed to go well beyond the first 1000 days. “We need to support children and young people past the 1000 days – so many other issues later in life and mentioned in many priorities could be addressed by providing better health care, support and education to families.” “If we get it right for them, it will have long lasting benefits for the population and the system.”

This also linked to a focus on education and prevention. “We should invest more in children, encourage healthy lifestyles, educate parents on home management (fever, minor illnesses) and support young families” and another believed that “early intervention to help parents needs a huge overhaul, was not fit for purpose and desperately need re-thinking.”

There was a fairly broad perception that health inequalities begin from birth and do not wait until adulthood before impacting upon the health and life chances of individuals and communities and there is “currently significant inequality of access to health care for children and young people in Lancashire and South Cumbria.”

A proportion of these respondents also expressed their concern for mental health and emotional support for children. “Mental health support for school aged children and more access to counselling during school.” Some felt there needed to be a “higher focus and increased funding for Child and Adolescent Mental Health. The services are underfunded and understaffed.” A range of respondents also expressed concern about the services for autistic children and children with learning disabilities.

Although these responses, in many respects, supported the priority identified, many went beyond this to cover children of all ages and their families.

Communication and collaborative working across all partners

Over 10% of those providing additional feedback commented on the need for better communication and collaboration between the partners and/or with the communities they serve. Some called for a full or improved integration of health and social care while others felt there was a need for partners to “work together as one,” and to be “on the same page.” One member of the public felt it was important that partners “do not fall into organisational bickering about ‘who is in charge of each of these priorities,’ and that we “agree how ‘we’ are going to work most effectively together to address these big issues.”

Although improved or better communication was often mentioned a significant proportion of respondents also referred to the need to share information and records better and to have systems that talk to each other. Others indicated that an improved infrastructure was needed before better partnership working can take place.

A few respondents, while recognising the requirement for “significant partnership work” wanted reassurance that “partners have signed up to these priorities” and an understanding that the “measure of success will be down to all partners.” It was also felt that there was a need to remove “bureaucracy and red tape” and “make the lines of responsibility really clear and transparent.”

One respondent felt these priorities have not changed “for around 15 years” and have been exacerbated by decisions made in the past. These pressures are “felt differently in different geographies based on the environment ‘people’ live in, so a local perspective and accountability is needed to help citizens of the area.”

This links with another area of feedback, the need for partners to work with and involve communities. “I think there is an overarching priority about listening, co-production, and working effectively with people and communities, particularly those with lived experience.” Partners “need to be accountable and transparent and communicate with the population and involve them in proposals and action.”

There was also a significant call for greater support and funding for VCFSE partners and an acknowledgement of the vital role they play in delivering many health and care services.

Many also felt there had to be improved communication at various levels, not just between partners in different sectors but also between partners in the health service. It

was felt that “improved communication between General Practice and Hospital care is essential. Improvements in more holistic care, with multiple departments communicating to discuss the patient as a whole, not in their individual ‘streams’ of care.”

Survey/priority issues

10% of these respondents expressed a concern with the survey itself and/or with the priorities chosen.

Some of the feedback received was general, in that it concerned the survey as a whole, and some was concerned with particular elements of the survey or of a particular priority.

A high proportion of this feedback indicated they felt the survey was “too rigid” and did not allow for people to submit their own choices and priorities. A snapshot of the comments made is included below:

“It would have been good to be able to rank all of the items in each list as many of the areas are important.”

“The option to choose one sub-topic in each category seems a little over-simplistic. A ranking option, perhaps limited to three, might provide a better picture.”

“You aren’t asking the public, you’re just putting ICB questions that suits your priorities without proper public consultation and thousands of your service users are being left behind and not given a voice because they don’t use technology or social media.”

“Some of these statements do not reflect the priorities of all the partners in the system and still focus on lifestyle improvements, treatment and NHS based issues when we need to be looking wider at preventing ill health.”

“They don’t mention increasing the health and care workforce, support for looked-after children, access to services for families with autistic or learning-disabled children, employment and skills for disabled adults, the poverty levels of the health and care workforce.”

Several respondents felt issues around the health and care workforce was overlooked but that little could be achieved without this being addressed. There was also a feeling that some of these priorities were “huge” and that tackling health inequalities, identified in just one priority area, ran through many.

Several respondents also expressed their concern that a range of key priorities were not mentioned or touched on in the “pre-determined list.” These include:

- increasing the health and care workforce
- poverty levels of the health and care workforce
- housing
- crime – reducing offences and ASB
- failings in GP Practices regarding Chiropody Services, Eyes and Hearing Care and general wellbeing of older people

- increasing the number of hospital beds
- more easily accessible urgent care
- more signposting to services and advice
- positive parenting and reducing the impact of adverse childhood experiences
- support for looked-after children
- access to services for families with autistic or learning-disabled children
- employment and skills for disabled adults
- improving support to challenge poor employer practices
- holistic support for the family
- leisure/open spaces – provision of facilities, especially for our young to be occupied and active

Several respondents also expressed their view that “a lot of the work of the ICP will sit outside of the NHS, in social care and specifically in the VCFSE, where resources are needed to ensure the priorities identified can be achieved.” An indication that some at least, felt the priorities dominated by the NHS.

The feedback, and frustrations, of this group of respondents can be summed up by indicating “we have so many of these documents, plans, strategies etc. which all promise ‘a real focus on putting people first’ or ‘preventing ill health through early intervention’ and so on and so on; when will we actually see significant and crucially sufficient resources including people, money, services and assets oriented around these priorities in terms of strategic planning, workforce development, purchasing and evaluating? I’ve only been at this a little over 13 years and it’s not happened yet, despite many pretty documents.”

Access to services and workforce issues

Over 10% of these respondents raised one or more of several inter-linked issues relating to access to services, both in general terms and in more specific points concerning resources, infrastructure and the wider determinants of health. Respondents often referred to equity of access to services and the barriers that prevented this, including poverty, knowledge and education, language, transport and locality. It was felt that we should be “creating services and systems that are accessible and work for our citizens not just the organisations and institutions that deliver the services.”

Access to a GP was the service most frequently mentioned by respondents, but other services were also mentioned, including:

- social care
- health visiting
- dentists
- children’s hospital (the only one is outside our area)
- early intervention services
- support services for children and adults with autism and learning disabilities
- CAMHS

- community centres
- hospitals

When mentioning poor access to GP services some respondents felt the priorities did not address the “crisis in General Practice: workforce, workload and estates,” which need “urgent attention.”

Others also mentioned workforce issues as a significant contributor to the poor access to some services. For example, “there is no mention of the health visiting service which has been depleted over the past 10 years to the sad state it is now.”

Poverty was considered one of the major barriers to access and there was a call from several respondents to target support and delivery to more deprived areas and to those more marginalised groups: BAME; asylum seekers; LGBTQ; homeless; people with learning disabilities. Although tackling health inequalities is discussed further below, for several respondents, improving access to services meant tackling these inequalities and ensuring there was “increased social support for all people who are at risk/vulnerable, regardless of age.”

A relatively high proportion of these respondents also felt transport was a major concern, especially for those in more rural areas; “people in more rural areas do not have access to care and are often cut off due to lack of public transport.” “I recently had a family member bed blocking in hospital because it was impossible to get carers to his village and as a public transport user myself, I could not get there to help.”

It was also felt that deprivation was considered an “urban” issue, but that it can be just as significant in rural areas. This also related to calls for services to be local or to keep them local. New hospitals were fine, but they tended to serve urban populations not those in rural areas.

Wider determinants of health

8% of these respondents focused on the wider determinants of health. A little less than a third of these referred to the cost-of-living crises and that this, and its impact, was a major priority over the next 12 months. Indeed, for one respondent, the consequences of fuel poverty and increasing levels of indebtedness meant the existing priorities “have been developed six months ago and the world has changed since then.”

In addition to comments on the cost-of-living crises and poverty generally, a proportion of respondents also felt employment was a key priority. “Getting people into work is key to everything” as “employment has a huge impact on health and wellbeing.” “It helps people’s self-esteem/mental health, their economic wellbeing, access to leisure, healthy diets and lifestyles.”

There was also a range of comments around increased access to good social housing at reasonable rents and improvements to housing generally. Some respondents, however, were keen to link improvement in accessing good housing, and better employment, to other improvements in some of the wider determinants of health and the infrastructure to

support it. Reference was also made by several respondents to new house build projects and lack of services (health, schools, community facilities etc.) that went with them was only putting pressure on these services and building problems for the future.

Mental health, learning disabilities and older people services

Although three different service areas some respondents grouped these together as part of their feedback on services that needed further development, resources, or a higher priority.

Mental health was felt to be a top priority by over 5% of respondents and applied to all age groups. Some respondents felt “we are in a mental health crisis that appears to be ignored by the majority,” and “impacts every area of an individual’s life.”

Respondents also identified several issues that impact upon our mental health, including loneliness and isolation (“a killer as serious as smoking”), gambling, drug and alcohol abuse and, most importantly for a smaller group of respondents, dementia. For the latter we needed to “fix the holes in the care system and the impact on families,” and ensure the memory service was “working closer with GPs when patients are discharged.”

Others also felt there should be “more care, consideration and support given to families living with someone with a learning disability,” and that we should “strengthen GP signposting to services for those living with disabilities.”

There was particular concern for people with autism, and that we should “consider separating out autism from learning disability.” Other feedback on this issue concerned the families and carers who support and live with those with autism, “listening to them when they say they are in a crisis situation,” and understanding that “the level of support available to family members who care for other family members is not sufficient.” There was a call for giving priority to parent carers, unpaid carers and young carers.

Although a slightly different issue, it was also felt by some respondents that “we are not focused enough on the increased ageing population” and that community and support services for older people, even giving them places to go and gather socially, required greater input and priority.

Prevention and health inequalities

5% of respondents who provided written feedback mentioned prevention and/or health inequalities. It was felt that there needs to be an “emphasis on health promotion and prevention,” but the priorities seemed “very light on Public Health issues.” It was felt that more effort and “funding in preventative approaches in, and across, the NHS” needs to be given and that people need to be given the tools to take responsibility for their own health.

Touched on previously, some respondents emphasised the requirement to tackle health inequalities and the need to “work closer with vulnerable groups” and involve “hard to reach communities.” Some specific services were also mentioned, including cancer (“I

am surprised to see no objective around cancer considering we are one the most underperforming countries”), stroke, heart disease, obesity, mental health and sexual health.

One respondent was concerned that “health inequalities will continue, and that Lancashire will be prioritised over Cumbria, in particular South Lakeland.”

Other themes

A few other themes were raised by a relatively small number of respondents, but sufficient for them to register. These concern end of life/palliative care and investment in social care.

Mentioned by 2% of respondents to this question, several points were raised regarding end of life/palliative care. These included:

- prioritising funding to achieve an effective electronic end of life care co-ordination record (EPaCCS)
- hospices under funded and not an equal partner
- the resources to support dying well at home are not in place

These respondents felt palliative care “needs a vast improvement” and there needed to be “more support for the family within ‘dying well’.” “People want to die at home, but only if they have the right level of support to enable them to die well – this means adequate social support, good carer support as well as nursing and medical support. This needs enough workforce to meet these needs, and for those staff to be appropriately trained. The workforce issues and the training (within health and social care) would have the most impact.”

A similar level of respondents felt social care services were the first priority, with a need to improve access and to see better pay for social care staff to improve its attraction as an area of work and to address the “chronic shortage of capacity in care at home and residential care.” There was also a call for “a dedicated person for each person to speak to, who can advise on all aspects of social care” for those who need it.

The point was also made that many people confuse social care with the NHS and believe it is free at the point of service, which means “so much time and resources are used to explain that social care is means tested.” There is a need to “dispel the urban myth regarding ‘6 weeks of free care’.”

Finally, in respect of those who had something to add to their responses, there were a few individual comments of note. These are included below:

- digital deprivation was mentioned and, while not undermining the need to enhance digital solutions, it was important that we remember or learn “how to communicate effectively with people who are not IT literate or do not access a smartphone or the internet.”
- there was no mention “under the Living Well category of reducing waiting times for surgery in the NHS.”

- under the Living Well section “supporting domestic abuse victims was too narrow and needs to include all people who have experienced sexual violence. The impact of sexual violence (not just domestic violence) causes long term mental health problems, physical ill health, financial difficulties and can lead to loss of housing and suicide.”
- “the systems that people are working in/with are not supportive of delivering the accessible, easy in easy out responsive pathways/services that are needed to support the increasing number of people across our divers geographical footprint.”

What one improvement would you like to see, based on these proposed priorities?

Response levels

479 (65.3% of all survey respondents) provided a response to this question.

Of these, 234 (48%) did not work for one of the organisations in the Partnership.

255 (52%) of respondents who provided additional comments indicated they worked for one of the member organisations. On balance therefore, approximately half of the comments provided were from members of the ICP.

In respect of organisational breakdown, of those providing a response to this question:

- 39 (8.1%) were from local government
- 161 (33.6%) were from the NHS
- 16 (3.3%) were from hospices
- 2 (0.4%) were from universities
- 20 (4.1%) were from VCFSE organisations
- 3 (0.6%) were from Healthwatch
- 9 (1.9%) left this element blank

In terms of ICP membership therefore, most responses came from NHS partners, as previously. Similarly, from within the NHS the highest proportion of comments received were from NHS Trust staff, with 100, 21% of all those who provided their feedback to this question.

Themes

Many of the themes, issues and topics mentioned in response to the previous question were raised again here, with much of the feedback repeating or adding little to the responses already given. Although asked for one improvement some respondents were

unable to do so and mentioned two, three or more areas. As there were more respondents to this question, some issues became more prominent.

The themes raised included the following:

- Children, young people and families – this was again the most prominent area of service and support, with over 11% of respondents. Some of the main points raised in this respect concerned
 - Support for children and families in areas of deprivation or in poverty
 - Providing the best start in life, with even more calls for the return or expansion of Sure Start centres or by creating “children’s hubs”, where integrated services would provide “a more comprehensive, cohesive whole system service”
 - Greater support for education and prevention, “with more joined up strategic thinking between education, health and social care”
 - More requests for improving health visitor services, including having “a named Health Visitor who has a local caseload and regularly communicates with the local medical practice/GP”
- Closer working, communication and integration between health and social care, and other partners, was on a par with the above, and included
 - Improved communications
 - Greater collaboration, honesty, and openness
 - True integration of services and budgets
 - Shared systems and information
- Improved or more equitable access to services, which over 8% of respondents mentioned. This included
 - Access to services generally
 - GP services
 - Mental health and related therapies
 - Almost half of these responses mentioned improved or better access to social care
- Tackling or reducing health inequalities
- Prevention, including
 - Investment in prevention services
 - Improved support and lifestyle guidance for parents-to-be
 - More emphasis on supporting and educating people on the benefits of looking after themselves to prevent illness
 - GPs, hospitals, care workers etc to be more pro-active with regard to illness prevention
- Community services, with investment in quality community care pathways/services and better supported community solutions, with better signposting and advice and, more importantly, more hands-on community support services
 - “There needs to be investment in quality community provision such as diagnostics to shift the balance from the acute settings to community care” and “24-hour coverage of district nursing or similar services.”

- Ability to “access relevant investigations or documentation when patients are being transported between hospitals and between community services and acute services.”
- Social care services – improvement and investment in social care was specifically mentioned by over 8% of these respondents, and included
 - Accessible and affordable care homes
 - Improved access to social care support for older people
 - Better pay for care staff, paying them “above what local coffee shop and supermarkets are.”
 - Almost half these responses mentioned greater support for unpaid carers “whatever age they are and whichever family member they are caring for and whatever the family members problem is.” First-hand experience of feeling “isolated and ignored by health professionals,” and getting “no support from anywhere and it’s utterly exhausting and soul destroying.”

These were the most prominent themes. Others mentioned largely echoed those covered in the previous question, including

- poverty (especially food and fuel poverty)
- end of life/palliative care
- care for older people
- mental health
- employment
- housing and homelessness
- dementia
- learning disabilities and autism
- more equitable funding and involvement of VCFSE organisations as an equal partner
- a greater emphasis on holistic care and service delivery
- and improving life expectancy.

There were a few additional points made that are worth noting, not found elsewhere in the feedback provided. These were:

“This survey should be written in plain English. Half the population won’t have a clue what you’re on about.”

“The priorities and issues are all laudable and I recognise the visionary nature, but they also seem to lack being grounded in reality.....Feels like a bit more pragmatism is needed otherwise they fall into the trap of not being unachievable. Would be interesting to ask the ICP Board how they would measure success.”

“It is imperative that effort is made to fully understand our population and their needs and most importantly ensuring that those who are disempowered and disengaged are involved before any actions are agreed. We must also work more closely with research partners in our universities, particularly within health and care settings, to ensure that any actions are evidence-based and are properly evaluated.”

Conclusion

Although there was a significant level of support for the priorities identified this was by no means unanimous. A fairly high proportion of respondents found it too difficult to identify priorities because they were all important, testament perhaps to the challenge we are facing. Others expressed their concern about the priorities being pre-determined, dominated by the NHS, not sufficiently focused on, or involving communities, or failing to recognise some key drivers such as the cost-of-living crises and waiting lists.

It was recognised that the need to work together as a system was paramount, but there was also a strong call for various key services to be strengthened or developed, with a particular emphasis on supporting all parts of the system to deliver care, including carers, both paid and unpaid, services with depleted staffing and resources (GPs, Health Visitors, community nursing, care home staff), voluntary, community and charity organisations, and patients and their families.

There was a broad feeling that access to many services needed to be improved, both in general terms and in respect of equality of access for many groups, including those with mental health, learning disabilities and autism, other marginalised groups and, most prominently of all, children and young families. There was also fairly robust support for need to tackle health inequalities and put a greater emphasis on prevention, health promotion and education, together with the need to tackle, before or in tandem, the wider determinants of health.

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