

Guildford & Waverley Integrated Care Partnership

Shaping citizen and patient involvement

June 2020

If you would like this report translated into another language or alternative format such as large print, Braille or audio, please contact us using the details in section 9.

Please note:

Analysis and review of the feedback from this event had to be postponed from earlier in 2020 in order to free up resource to respond to the COVID-19 pandemic

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1. Guildford and Waverley Integrated Care Partnership

Guildford and Waverley Integrated Care Partnership is part of Surrey Heartlands Integrated Care System, which works in collaboration with Surrey County Council. There is now one Clinical Commissioning Group (CCG) covering the whole of Surrey Heartlands.

Guildford Waverley ICP is a place based, collaborative partnership of local health and care organisations working together to improve outcomes for our local population on an area basis. The partners include:

- NHS Surrey Heartlands CCG
- Surrey County Council
- Guildford Borough Council/Waverley Borough Council
- Primary Care Networks (PCNs) x 4
- Surrey and Borders NHS Foundation Trust
- Royal Surrey NHS Foundation Trust
- Procure Health and ProCare Community
- SECAMB
- Voluntary, Community and Faith organisations

As a partnership, we have a shared vision for: *“Guildford and Waverley population to start well, stay and live well, age well and die well. We will build resilient and empowered residents and communities through networks of stakeholders and together steer and oversee design and delivery of integrated health and care services. Improve outcomes and extend our opportunities to prevent illness to our communities. We will support people to stay longer in their own homes.”*

2. Workshop for partners and stakeholders

In January 2020, members of the Patient and Public Engagement Group and the Patient Participation Group Chairs Network for NHS Guildford and Waverley Clinical Commissioning Group were asked for their thoughts regarding how the new ICP could involve citizens and patients in its work. Given the range of stakeholders in Guildford and Waverley is far greater than the membership of these two groups and taking into account the desire of the ICP Board to build in strong and innovative stakeholder involvement, there was broad and enthusiastic support for a one-off workshop to start to explore this very theme.

A wide range of stakeholders in Guildford and Waverley were invited to register for the workshop on Eventbrite. It was held at Godalming Masonic Hall on 3rd March 2020 from 1.30pm to 4pm. The Masonic Hall is an accessible venue with free car parking and has been used before by the CCG with good feedback from participants.

44 people registered on Eventbrite to attend. There were a handful of cancellations on the morning of the event. In total there were 41 delegates who took part in the workshop, many of whom were representing groups and organisations including the following:

- Surrey County Council
- Guildford Borough Council
- Sight for Surrey
- Voluntary Action South West Surrey
- Action for Carers
- Oakleaf Enterprise
- Citizens Advice Bureau Waverley
- Age UK Surrey
- Patient Participation Groups (Shere, Haslemere, Milford & Witley)
- Crossroads Care
- Healthwatch Surrey
- Surrey Coalition of Disabled People
- Diocese of Guildford
- Royal Surrey Hospital NHS Foundation Trust
- Disability Initiative
- SMART Cranleigh
- Headway Surrey

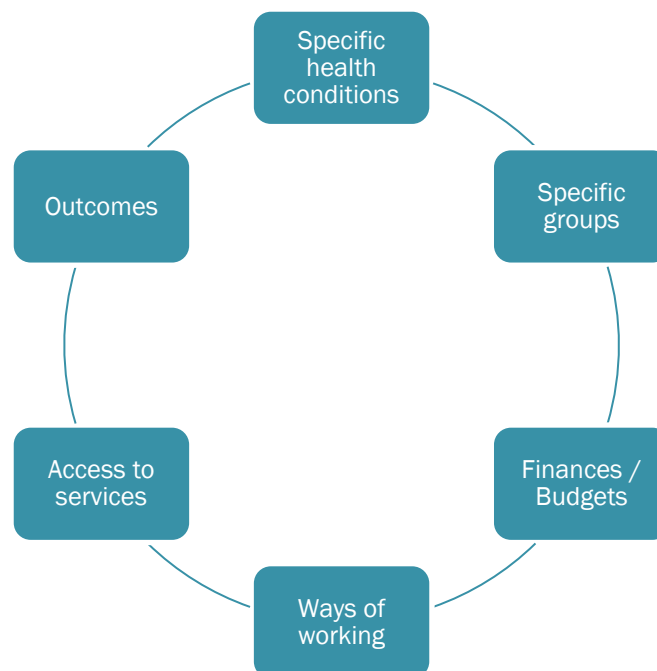
A [presentation] was given by Giles Mahoney, Guildford and Waverley ICP Director and System Lead for Cancer and Stroke. This was followed activities aimed at seeking views from delegates regarding the ICP.

The feedback from each activity has been themed according to prevalent categories. These themes are presented described in the next few sections with all comments related to each theme being available to read in the appendices.

3. Priorities and concerns

Two activities asked participants to identify firstly, what they felt the ICP should prioritise and secondly, what concerns them most about the ICP. These two sides of the same coin help to identify what is most important to those who attended and what they think could prevent the ICP from doing something concrete about their priorities.

Across both activities, there were six broad categories that the majority of priorities and concerns could be grouped into as illustrated in figure 1.



Mental illness and vulnerable groups were dominant concerns and priorities for participants, particularly:

- Social isolation and loneliness
- Support for carers, particularly young carers and those looking after relatives with dementia
- The Gypsy, Roma and Traveller (GRT) community
- Homeless people
- People with brain injury
- Refugee families

Financial priorities and concerns related to individual areas such as Personal Health Budgets and Personal Independence Payments to how finances may be worked through as an ICP to fairly fund areas of concern so that health and social care needs are addressed at the same time.

There was clear support for coordination and removing silo working between organisations and groups of staff as well as a common commitment to compassion and understanding.

Accessible services were a key priority – there was a strong call for organisations to make their communications accessible to all, as per the Accessible Information Standard alongside ensuring that care is delivered as locally as possible.

Finally, there was a firm emphasis on outcomes – making sure that the ICP delivers concrete, measurable improvements. Several were proposed, as follows:

- Improvement in housing standards; protected key worker housing
- Improvement in air quality
- Reduced health inequalities

A full breakdown of responses can be found in appendix 9.

4. Hopes and Fears

Next, participants were asked to identify their own particular hopes and fears for the ICP, given the new ways of working it is designed to enable, with local authorities, providers, the voluntary sector and the commissioners all committed to working formally together. Not surprisingly, the same themes arose as illustrated above (figure 1).

Integrated care, seamless experiences and financial recognition of social care and voluntary organisations stand out as key hopes for the new way of working. Across all themes, there was a clear call to move from a purely medical/health care dominated approach to a societal model that recognises the many and varied determinants of health and ill-health. Early intervention and placing individuals at the centre of their care were also highlighted as key hopes. Fears included the ICP not learning from the past, short-term solutions i.e. a lack of sustainability and voluntary organisations not being fully recognised and compensated for the roles they would be asked to play.

A full breakdown of responses can be found in appendix 10.

5. How should the ICP involve its citizens and patients?

An important aim for the workshop was to shape how the ICP should set about involving its own citizens. Involving patients and the public is a statutory duty for health and local government organisations. The ICP wants to develop this key aspect of its governance with imagination and base it on best practice and evidence.

Participants were largely very enthusiastic and supportive of the ICP taking a fresh approach to engagement and involvement in order to ensure that those groups variously described as 'seldom-heard' or 'hard-to-reach' are fully involved in developing solutions to the problems and hurdles that they experience; problems that can negatively impact on health outcomes.

At the same time, existing stakeholders were keen to ensure continuity of involvement, whether that be via regular forums or events such as this one or via regular and varied communication methodologies.

Genuine co-design that pulls people together to solve a particular issue; that reaches out into communities was described; a continuous form of engagement that uses different, tailored methods dependent upon the intended audience

One group stood out across the feedback as requiring a different approach: children and young people. Whilst key programmes such as mental health and maternity involve children and young people it was felt that more could and should be done to more generally involve this age group in a broader range of programmes. This would require a much more creative and targeted engagement approach that reached out to them.

Full details can be found in appendix 3.

6. Next steps

This report will be discussed at a future ICP Board meeting at which members will describe how they will incorporate the feedback into the development of the ICP itself and its programmes. An engagement plan will be agreed that incorporates the suggestions put forward for involving citizens in the ICP.

The report will be published on the new NHS Surrey Heartlands CCG website.

7. Contact details

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8. Appendix 1 – Priorities and concerns

8.1 Priorities

The following were identified as priorities for the ICP Board:

8.1.1 Specific conditions/groups

- Mental Ill Health
- Mental Health pressures – young people
- Mental health services – lack of communication/integration
- Isolation
- Challenges in wealthy rural areas – assumption that deprived areas have more need.
- Young carers need to be able to access appointments for themselves quickly – need to be taken seriously and consulted face to face – given responsibility for themselves
- Frail and elderly at home not in hospital
- Barriers in disability
- Dying well – what are we going to do?
- Headway Surrey – need health and social care workers to know about brain injury support in the community – social prescribing is no use, if the adult won't seek help from their GP!
- Stronger links with stroke

8.1.2 Finance/Budgets

- Personal Health Budget – Health and Social Care.
- PIP (Personal Independence Payment)
- Extension of support/funding for Surrey's unpaid carers
- Funding barriers – health solution – Surrey County Council personal health and social care joint
- Personal Health Budget – Health and Social Care.
- Join up care – health and social care budget from the top

8.1.3 Ways of Working

- Co-ordinated care (get rid of silo)
- Compassion and understanding
- Co-ordination – family – mental health and health
- Link community to GP practice (two-way link)
- Better work with providers
- Who does what in between agencies – joint training.

8.1.4 Access

- Where to go for support/advice?
- Technology – help lonely – smart TV?
- Accessible information – deaf people – 2-way text system
- Increased use of community facilities for specialist/health professionals to provide local delivery some days a week
- Communication about where to go for treatment – 111? UTC? Etc.
- Communication – how do we get our voices heard?

8.1.5 Outcomes

- Need local focus – can't do everything.

- Protected key working housing
- Housing standards
- Look beyond the statistics – i.e. why do people smoke, why are people overweight.
- Real change for real benefit.
- Air quality – borough and Surrey County Council can influence this and must include NHS involvement in this discussion?
- Health inequality – income
- Enabled, empowered, educated, informed.

8.1.6 Engagement/Involvement

- Let us have a monthly 2-hour session at appropriate venues.
- Some PPGs do use leaflets to their patient population to announce initiatives e.g. social prescribing, if this doesn't happen everywhere, perhaps it should?

8.1.7 Workforce

- Care Staff

8.2 Concerns regarding the ICP

8.2.1 Finance/budgets

- Benefits
- What does it mean – Partnership – Same budget not just telling
- Confusion for people over funding
- Money – easy to listen /harder to implement
- Education of continuing healthcare – CHC how it works with training
- What is financial context of ICP's within Surrey Heartlands ICS? Is there a target for savings? How long term are the schemes being announced for the changes talked about in ICP strategy? (eg £2m for 2 years for “out of hospital”
- Funding for PPG groups
- Concerns of privatisation
- Cuts in services and rise in thresholds = complexity of cases being undertaken by for example the voluntary services providers
- Universal credit and its impact.

8.2.2 Ways of working

- Different systems (MV, Guildford) – Repeat Story – repeat blood tests
- Lack of consistency in clinical pathways
- I & A can this be embedded across the ICP (particularly who can do what)
- Continuity of care, good level of care has been lost.

8.2.3 Specific groups/conditions

- Loneliness/inter-generational (older people)
- Early years stress – (young children, primary school)
- Respite care – (older carers)
- Dementia Care – ageing carers (tying up various activities)
- No clear pathway for brain injury for health or social care – hidden disability not picked up immediately
- GRT (Gypsy, Roma, Traveller) community and other groups who may have specific needs

- Mental health – what is available at each level
- How will we support our refugee families with health needs and access to services (taking on board language and cultural barriers) particularly mental health
- Concern that carers are not forgotten when planning care for patients
- Homelessness – mental health
- CCG should recognise that benefits is a mental health stressful issue
- Mental Health
- Poverty – mental health
- Suicide amongst unpaid carers particularly adult carers and young people 16-25
- People on the edges – no-where to go
- Gender gap – poor women versus wealthy women.

8.2.4 Access

- Homecare – different quantities across Surrey
- Transport (lack of access – care –cost (Cranleigh Village)
- Transport from Elstead to Royal Surrey County Hospital
- Local delivery very important.

8.2.5 Outcomes

- How do we get feedback on outcomes?
- Statistics used are misrepresenting impact of clinical services – a lot more complicated picture that suggests its someone’s fault if they are ill.

8.2.6 Workforce

- Libraries! The word does not appear in the Surrey County Council health and wellbeing strategy. They are run by librarians/volunteers who are willing and able to help. Much more use could be made of this resource
- Implications for workforce of plans to treat people “out of hospital/keep people at home” which will be less efficient in terms of productivity – effect on staff morale/burnout.

8.2.7 Governance

- Change and improvement discussion fatigue (we’ve been here before)
- Transparency concerns re the impact of proposed changes
- Concerns that Surrey Heartlands too big – lose local priorities
- Landscape too complex.

9. Appendix 2 - Hopes and Fears

9.1 Finance/budgets

Hopes	Fears
Integrated care – budgets easy to access – not health or social care.	Wasted money
Personal budgets for LTNCs	Finance – good intentions but not enough money to follow through
Increase in voluntary sector funding	Over reliance on volunteers as “cheap” solution
We genuinely share resources, intelligence across and between organisations	Brexit leading to increased health privatisation
Increased support through PIP applications	Over-reliance on voluntary sector who are already stretched to their limits – resources/finances
Better use of SCC buildings that are under-utilised. Free use to charities.	Expecting voluntary sector to pick up slack with no funding
We have all the money we need to give good quality care and support at the right time to anyone in Surrey.	Two tier NHS – only core services provided freely – increasing amounts requiring payment/insurance top up
End to privatisation	Money spent in the wrong places
Social care to be publically provided	Who is responsible for which bits? Are the partners equal partners? Risking that it becomes a dictatorship with NHS dictating (because they hold the budget)
That a major programme of social housing will come about	Re-organising costs – money
Joined up funding	Voluntary sector cannot pick everything up – lack of funding
An integrated approach to signposting those people and their carers dealing with benefits	Funding reduced to voluntary sectors (social care budget cut therefore loss of referrals/funding)
That community based initiatives will prove successful and that there will be sufficient money available for them	Voluntary sector needs to be funded to provide additional services if this is to be expected
	That necessary funding jointly across health and social care will not come about
	Biggest fear is that ICP will be outsourced in entirety to private sector, e.g. trade talks with States with NHS on table. ICPs same structure as USA’s hence the concern
	Short time funding – great ideas often take a while to get going and embed in day to day life. Funding is too short to get through this embedding period.

9.2 Ways of working

Hopes	Fears
<p>Better information sharing between health and social care</p> <p>Less duplication and better knowledge of across agency services</p> <p>Better use of technology</p> <p>More joined up working/care</p> <p>Genuine integrated care</p> <p>That integrated care across primary, secondary, tertiary care and voluntary, Local Authority etc. works more effectively</p> <p>That there will be no more major administrative reorganisations</p> <p>Only having to say it once – joined up working between health and social care</p> <p>Better joined up care</p> <p>That the ICP enables (and encourages) cross-sector working to benefit the people in G&W (and Surrey as a whole) as health needs and social needs are never in isolation and are always connected</p> <p>To cut back on duplication, where every service knows what their role is and who to hand over to, to create a chain of support where the client and carer know who's responsible and who to talk to</p> <p>Respect and training re: carers and confidentiality</p> <p>Focus on the person not the process</p> <p>Use 111 to sign people to the service they need.</p> <p>Use community hospitals more effectively – client experience will improve as it will reduce transport stress.</p> <p>An integrated service</p>	<p>We use IG as an excuse not to work together</p> <p>Repetition of peoples' experience</p> <p>Duplication of projects rather than integration of projects</p> <p>Not learning from the past</p> <p>That I will be isolated at home and the potential for technology to link me with social networks will not be realised</p> <p>Voluntary organisations not involved and supported in supporting clients</p>

9.3 Specific conditions/groups

Hopes	Fears
Respite available for LTNCs in local area	Poor access for deaf/hard of hearing people to use the 111 service. Need to use a 2-way text system too
More consistent support for individuals suffering mental illness	Isolation – transport links disappearing CAMHS – not fit for purpose in Surrey – 11-18s not able to access support when it is needed
Increased investment in 18-25-year-old mental health	Cuts in funding for individuals who need social care for brain injury. Already happening and anticipate it will get worse.
That money will be found for supporting the frail elderly	Would like focus on carers not to be forgotten, particularly in the older age group and young carers
Early intervention in mental health	Clients with LTNC not able to access services and expected to access services that do not have expertise to support them
More education around mental health in schools, colleges and universities	Problems with applying for benefits create stresses for people e.g. PIP
Start educating people early in their lives (i.e. when they start school) about healthy lives and the impact of smoking, drinking, eating a poor diet and their responsibility to helping others to do the same.	No action on mental health support No tactics to prevent suicide (universities all handling it differently) It is the waiting for answers that kills people Coping with benefits is disabling the population Mental health is going to remain the Cinderella of NHS funding The experience of mental illness at the beginning can be very traumatising. There is still stigma and little understanding in general communities about how mental ill health develops

9.4 Access

Hopes	Fears
Move to more community/local based services – better access to support	Disregard of accessible information – braille/BSL interpreters/large text etc
Continued commitment to building on partnership will make services more joined up and easier for people to access	Lack of resources in the community Transport issues
Seamless transition from health to social care community	
Access to services become easier and positive outcomes are achieved	

9.5 Outcomes

Hopes	Fears
<p>That societal inequality will be fundamentally addressed</p> <p>Grass roots of inequalities are addressed, e.g. “I smoke because I don’t have a job; rent is too high and my house is damp!”</p> <p>Residents will live and die better</p> <p>Prioritise desired outcomes and manage individuals’ expectation. One shoe does not fit all.</p> <p>That the ICP model enables clinicians and other stakeholders to deliver the care across settings, improve health outcomes, reduce health inequalities and see real change</p> <p>Measure outcomes against person’s experience (move away from being target driven) - person-centric.</p> <p>Real change that has a real impact.</p>	<p>Lack of sustainability of new initiatives</p> <p>Nothing changes</p> <p>Might not make a difference</p> <p>Difference in priorities</p> <p>Too ambitious</p> <p>Slow</p> <p>On a more specific level, it is ‘key’ that outcomes and learning from the ICP work is monitored and evaluated – not least to encourage patients, staff and volunteers to see the value of the work</p> <p>More change with no real impact</p>

9.6 Governance

Hopes	Fears
<p>That there will be a multi-agency ability to evidence, robustly and tangibly, the benefits of this work.</p> <p>Focus on things which will be achievable</p> <p>Lived expectations are picked up at the start of new funding opportunities</p> <p>Transparency</p> <p>Inclusivity</p> <p>Accountability</p>	<p>Lack of action</p> <p>Lack of credibility</p> <p>Same old, same old</p> <p>Lack of transparency about the SH ICP</p> <p>Organisation will be too complex – adding an additional layer</p> <p>Easy access (i.e. feedback to engagement participants) to the actions proposed that comes out of these engagement exercises</p> <p>The language used is very similar to HMOs in the USA. For those who are not convinced that the NHS will not, over time, evolve into this HMO model with private funding, this is a cause for concern.</p> <p>Through the chaos of change, patients and their carers will be forgotten</p> <p>Increased bureaucracy</p>

9.7 Workforce

Hopes	Fears
<p>Raise the profile of “working in care” in Surrey. Joint adverts/recruitment days etc.</p> <p>Genuine integration of health and social care and breaking down of contractual barriers to working together</p>	<p>Workforce</p> <p>Continued problem of finding good care staff, especially in rural areas - knock-on effect for effective hospital discharges</p> <p>This indirectly hurts the voluntary sector to support these vulnerable people</p> <p>All sectors of health and social care have problems getting and keeping well trained professionals and support staff. What cross organisations discussion/co-operation could take place to find ways to tackle this?</p> <p>Voluntary organisations having to provide ‘social work’</p> <p>That others are treated as poorly and without respect as I was upon the terminal illness and then death of my husband, followed by the deterioration and death of my father followed by the death of my youngest daughter. No department believed my story, only it wasn't a story, it is my life. Holistic care needed. Empathy and understanding</p> <p>More services/support required from voluntary sector that is already stretched</p> <p>Wellbeing of staff amidst more changes and staff shortages</p>

9.8 Engagement/involvement

Hopes	Fears
<p>User voice influences services potential of social prescription realised</p> <p>Ideas and new projects involve the voluntary sector at the very beginning</p> <p>We genuinely share resources, intelligence across and between organisations</p> <p>“Big Picture” – using voluntary sector more and trusting the voluntary sector to do a good job</p> <p>Hope that carers are included in plans</p> <p>Hearing about all changes – results of meetings</p>	<p>Less local input with CCG merger</p> <p>Lack of community understanding how system works</p> <p>Individuals not taken seriously</p>

10. Appendix 3 – Involving citizens and patients

10.1 Cross-cutting methods

- Working groups defined by theme e.g. poverty where various communities are represented e.g. carers.
- Forums with mixed groups e.g. university, church and Healthwatch.
- Would it be useful to create an independent citizen board/group to reflect the ICP?
- Sharing the existing data and intelligence from different organisations, e.g. quantitative, qualitative, in order to create a wider social care, health and community perspective.
- A group that is not just linked to Surrey County Council and NHS but representative of all. The CCG would be accountable for this; it could be like a scrutiny panel.
- Any groups need to have a specific purpose – what are you asking of people.
- Citizen panel locally.
- Problem solving – pull people together to solve a particular issue. (targeted correct groups).

10.2 Children and young people

- Use schools to get younger groups engaged.
- Use social networks to get to younger groups.
- Work with schools directly to find young carers.
- Attend schools – young carers
- Home School link workers
- Involve youth
- to promote in the ways they feel they would engage with.
- Community development workers and mayors.
- Local schools via activities to help pupils think about their local community and healthcare arrangements.

10.3 Use existing forums

- There are a range of forums and groups that already exist: - use these existing groups for engagement.
- Find organisations who are working with the groups you need – most have newsletters that always need articles – ask to have notices added.
- Community conversations – community cafes – using existing local organisations.
- CCG staff attending more regularly local disability and older people forums as these people are likely to access health services on a regular basis.
- Use Surrey Chambers of Commerce or BID Guildford to reach working age people.
- Cranleigh lions style organisations use community.
- Speak to WI
- Women’s Institute (WI) etc, community networks/partners.
- Engage with care at home agencies within your area!!

10.4 Logistics

- Use different methods dependent on audience.
- Depends on what the engagement is about and finding target groups.
- Tailor engagement to specific groups.
- Genuine co-design.
- Must asked 'lived experience' of what you are working on for expertise and promotion
- Networks
- Make clear pathways to feed information into the system.
- Patient groups – virtual and face to face.
- PPG's – but citizens not representing themselves – are these channels clear for citizens to feed into.
- PPG – Chairs
- PPE's
- Existing PPEG worked really well – could expand with representation from other groups.
- Use a local approach to reflect communities.
- Using council chambers to hold meetings.
- Realistically will people want to attend meetings in the evenings? May lose professional engagement.
- Concrete not abstract questions to be put to citizen groups.
- PPG – Use as liaison and communication – virtual – need guidance and direction lots of goodwill – speaker at PPG event.

10.5 Communications

- Magazine – monthly? – link with parish newsletters/magazines.
- Asking councillors to spread the word to their network.
- Newsletter – who is this for??
- Provide 'Standard text' for event promotion ask everyone at the event to tweet about it.
- All joining in as a good example – directory of services.
- Use Eagle Radio, BBC Surrey.
- Make information accessible to all (not all online)
- More research must be accessible; must be consumer oriented.
- Better use of social media.
- Better understanding of where people get their information from.
- Website – think about what residents need to know and incorporate ASC information.
- Pull in existing feedback channels e.g. Healthwatch/PALS.
- Social Media.

- Using your engagement feedback wisely and disseminating your results back to the community that you asked, so that they understand progress happening.
- People are generally interested in change and like to talk to their friends and family about it 'word of mouth' by clever dissemination of information on what is happening in their local area.

10.6 Hard to reach groups

- Use keyworkers who already work with them.
- Reaching those who don't see the benefit of being engaged with/ trust in
- Using existing networks.
- Find a list of membership organisations that represent different groups –
- Age UK/Sight for Surrey/Surrey Coalition/Churches/INHN and sending them a specific question (like a mini consultation) ask them to ask member responses to them which they can feedback to you, so you know you get some response from hard to reach groups. Most voluntary/faith sectors already have networks you want to engage with and have trust built already.
- Making an assumption that people want to engage – only likely to want to engage if things are bad or already regularly engaging with health service.