

Finding Our Voice 2 – Let's Talk About the NHS

17th April 2023

The Street, Scarborough

Attendance: 35 people attended the event from a mix of organisations, institutions and individuals

Participants were asked to use post it notes, and conversations with other participants, to identify issues and concerns with various areas of the NHS / associated services.

Social Care

- Discharge from hospital
 - Disconnect between hospital discharge and the availability of social care places
 - Lack of communication
 - Delays in getting social care plans
- Cost of social care
- Availability of social care
 - Lack of capacity
 - Only top level needs assessed
 - No social care for under 60s with arthritis
 - Lack of support for carers dealing with violence from people with dementia (lack of support for those with dementia and their carers generally)
- Family carers
 - lack of NHS recognition of carers' expertise
 - not valued
- enrichment activities outside of care settings
 - hard to find
 - difficult to access
 - without it, a real risk of social isolation and deterioration of conditions
- social care / social care workers
 - underfunded
 - overworked
 - underpaid
 - lack of training
 - staff shortages
 - not empowered to make decisions in best interest of patient

Mental Health

- lack of services for children and young people
- no services for people who work / out of hours services
- assumption that people with SMI (serious mental illness) do not work or want to recover

- lack of counselling
- lack of personalised care
- very limited support for SMI
- 'knit and natter' is NOT therapy for SMI
- VCSE provision:
 - inappropriate signposting / referrals
 - when funding VCSE there is an assumption we can do it on the cheap, no respect for the true cost
 - independent grant funders will not pay for statutory provision
 - need for professional support for MH workers in the VCSE
- lack of bereavement care

Connections between primary care and secondary care

- poor communication
- misunderstanding throughout the system of roles and responsibilities
- need for 'navigator' – named consistent contact
- one-stop webpage with signposts to non-medical support
- no holistic / personalised care for people with multiple / complex conditions
- loss of services locally – cancer, stroke
- continued cancellation of appointments
- shortage of GPs
- ridiculous delays – 72 weeks for neurologist; 52 weeks for cardiologist!
- Unexplained rejection of GP referrals by secondary care
- Continuing use of snail mail rather than e-mail causing further delays
- Lack of action – patients having to chase up within systems they don't understand

NHS dentistry, audiology, podiatry etc

- Continued cancellation of appointments
- Lack of dentists – not just NHS ones

GP services

- Access – continuing lack of face to face appointments, access becoming increasingly more remote
- No consistency between practices – some are truly great, some truly awful
- Lack of continuity of care – never seem same GP twice
- No holistic / personalised care
- Lack of access for people who work
- Lack of advice / info / support for long-term conditions
- Digital exclusion
- Lack of understanding of menopause
- Stressful to work in a system where you can't deliver the care you want to a should be able to

- We need to feel we're in safe hands by having a GP who knows us
- Having a GP who really listens is lifechanging
- People aren't bothering to get the help they need in a timely fashion because the experience they've had trying to get care is poor or because they don't want to add further pressure to the system

What worries you about the NHS?

- Staffing
 - imbalance of management / clinicians
 - loss of morale / burnout
 - pay
 - parking charges for staff
 - recruitment
 - training
 - bureaucratic management – staff not empowered to lead solutions
- appointments and waiting times
 - specialisms moved from Scarborough – leading to transport issues
 - people go to A&E because they don't know where else to go
 - 111 is seen as 'hopeless'
 - Long waiting times and expectation of long waiting times means people don't go which can cause further problems in the future
 - People turn to online medication / self-diagnosis which can cause problems into the future
- Personalised care
 - people seen as a condition and not as a person
 - multiple / complex conditions not treated holistically
 - lack of time spent advance planning / finding what people want
 - quantity not quality of life takes precedence – over intervention and lack of patient choice
 - staff avoid difficult conversations with patients
 - lack of respect for lived experience
 - poor quality communications
 - unsafe discharge v no discharge
- VCSE plugging too many statutory gaps but not seen as equal or credible partners in improvement
- NHS culture which does not encourage change, presents rosier picture than reality, poorly communicates both externally and internally
- Lack of GP led community rehabilitation services
- Reintroduce convalescence wards
- Lack of investment, waste, poor investment
- NHS too fragmented
- Lack of confidence in the NHS – too big a problem to solve – 'it feels scary'
- Government forcing people to 'go private or die'
- Political direction of travel – government seems intent on making the NHS into a two tier system

Participants then co-created themes for further discussion with the intention of exploring:

- Things we can do for ourselves
- Things we could collaborate on
- Things that our outside of our ability to change that we need to raise

The five themes for discussion were:

- Personalised care

Personalised Care

Advanced care planning

- What is important to you
- What would you like to happen if you became unwell or end-of-life care

Dignity in dying website

GPs need to look at patient history on a yearly basis to just chat through what it means – give people a chance to talk about their concerns.

VCS could act as general problem solvers so that someone who has an issue but no local service can go to their trusted VCS organisation and find a solution – it might be that they are not IT savvy and don't know how to access information etc

Need for a named GP again who will know a person's history.

Need to better use the care coordinators in surgeries

Collaboration and Communication

- Directory of services – would require ownership from one organisation, buy in from other organisations to both use it and to populate it
- No wrong door approach
- More networking events

Self-Care and Resilience

- The pub
- Warm spaces
- Library – information
- Places in the community with consistent and reliable points of contact
- Befriending
- Friendship groups
- Social events
- Things for the isolated and housebound

- Access to green spaces

Our Voice – Campaigning

- Collaboration with other groups – strength in numbers
- Facebook – social media – big reach
- Having a place for people to voice their concerns, issues and ideas
- Need a consensus – less groups – 1 message
- Understand what else is available
- Need central hubs to access information
- Campaign to people who can affect change
- Communicate to those who want to affect change
- Using other campaigns to back up some messages

Caring for the Carers

- Respite for the carer and the cared for
- Carers plus
- Information for carers
- Network of carers supporting carers
- Why do care packages take so long
- Professional carers support

- Solution – self-help – facilitated support between carer groups

- Promotion of self-help / respite services available

Facilitator observations:

The 'caring for the carers' theme group did not address strongly the issue of professional carers – care workers, NHS staff etc although it was selected as a theme because of this – it is important that we respect and recognise the challenges workers in these settings are facing, not simply around pay and workloads, but about job satisfaction, empowerment, respect for skills and so on.

It was perhaps disappointing that there were limited community-led solutions proposed particularly in the areas of prevention, self-care, personal responsibility for health (even with one of the themes being self-care). It was also surprising that there was little reference made to the non-medical contributors to poor health such as poor housing, diet etc.

This is perhaps because the issue of the NHS has become so big that even a room full of willing and enthusiastic participants were so concerned by the direness of the situation that they could not think beyond it.

A follow up solution focused session could be valuable, based on the themes discussed and identified.