Greater Nottingham Transformation Partnership – public event table feedback

1 February 2018, Radcliffe Grange Hall

Table 1

- Integration is needed
- Individual not organisational
- Self-care / preventative
- Just because you have complex needs – not more
- Peoples needs fluctuate
- People need good quality info
- People experience fragmented and complex – need integration
- Wide police, fire etc
- Not support, enable
- Voluntary sector key – how can health / social care assist
- Principles read already on
- Outreach come where possible
- ? reduce choice e.g. sugar in diets
- Close to home – right place

Table 2

Sue McCabe, Wendy, Dave, Joyce, Janet, Cath

- Not joined up at the moment
- Moved around the system
- What support is there for carers – need a break
- Dementia – not joined up between health and social care and voluntary sector
- Need to identify care gaps so much out there but there aren't the workers – staff are so stretched. Cuts to social care
- Difficult to navigate through the system and then you have to fight for that service
- Should be a hub to direct you too
- Should be GP – but they dint have the time

Nicole – the care coordinators, one point of contact

The onus is on the patient – what about the people who can't do that

You need to support the carer

Need a care coordinator in each surgery

- We have care coordinators in the City is that being rolled out across South Notts
- Referred by GP – GP's can only suggest
- Need to get all GP's to sign up

How do we get some consistency in what we deliver?

- Prevention is better than cure
- Need well women and well men clinics / apps standardised across Greater Nottingham
- Proactive care and more patient info and more joined up
- Need to focus on young people and manage their expectations
- Better management of patients will be possible – looking at the support around the patient, is there time for that across Greater Nottingham – develop systems locally, time to be set aside to spend time to look at these patients
- Is the care planning part of the CQC – it's likely to be built in

Do you agree with the principles
Yes in principle but will it work in practice? Need social integration – peer support / self help and socially engage – gives people confidence / helps people live better.

Community network needs to be there – health visitors, community workers etc.

- Some conditions have more support and funding
- We need a system and services in the community
- Sharing

Appointments on line

- Where's the information available – not everyone is online/right information at the right time
- Need to identify carers and ensure they are seen quicker – can't take time for your own health

Families can't look after families in the same way – people work differently and away.

What's good

- Good experiences – test reminder / fantastic GP surgery
- Don't notice what is good – you expect it
- Late nights and early mornings

Table 3

Main points of feedback from our table:

- Aspirations are good but where is the detail? If a report is going to 5 February Council meeting then how can our feedback this evening be taken into consideration?
- How are decisions made? Why aren't families or individuals listened to? Example given of elderly lady having multiple TIAs and strokes. Ambulance insisted on hospital admission each time but all she wanted to do was die at home. Took 18 months before an accurate care plan was put in place. Does this system working address this?
- Workforce issues – this is a major concern and how are4 we addressing that?

- DNAs must be costing a fortune – how are we dealing with that?
- ACS – the elephant in the room – ownership of health – is a good step then people stop being patients and become citizen partners – where is this going?
- Role of national bodies and politicians – do we need to be lobbying for more tax from NI to fund the NHS properly?

Table 4

Mother 90 years old, dementia, blind, deaf at home with care, supported by IRIS team (four carers) No follow up, family had to fight for everything
Key principles

1. Failed
2. Yes, but family have to support
3. No people in hospital as no one know what to do

Son with MH disability
Carers via NCC

Care in own home sounds good, is it cost effective/efficient
Staff spend time in cars, travelling to homes
It is there to invest in these services

3 90 years old parents in laws
Demetria, arthritis, macular degen
Had to find out services themselves
They could afford to pay for day centre services, but some cant.
Misconception of a national health service, it is regional eg Wales, Scotland have free prescriptions
Though this part of the Country has better provision than other parts

Good experience of EOL care with integration between Nottingham City Council and Health
Condition became acute rapidly
Within space of a few hours there was 4 x a day care, hospice support, GP and District nurse care
Feeling that experience was lucky. Privilege of that level of care
Support for carers
Carers often struggle more with the patient's condition
They need support

The follow on care is critical
Care to get OOH is good, but it is the longer term care that can fall down.
GP's can't come out
e.g Ropewalk meant to visit annually but didn't, Therefore a new referral had to be made.
Carers often now in old age themselves and have their own conditions to manage.

Investing money doesn't have instant results
Need to train staff
Care home estate has deteriorated

Not just money, change is needed along with investment
Capability is there to join up wonderful care – sometimes

Fell over in garden, ambulance arrived in 8 minutes. Managed quickly in A&E but discharged very quickly with no follow on.
Each part of chain may work, but linkages broken
Had to ring around multiple consultants to find out who the person had to see.

Dr like mechanic – mechanics have moved on and have plug in diagnostics.

Lady dislocated shoulder had to queue with ambulance staff ad wait long time
Physio care was good

Received preventative advice as pre diabetic
Patient doesn't find session very useful and queried if this is fed back to GP
Appears fragmented and unclear who is accountable. People are passed around between organisations.

What has moved forward is preventable health
More from National Sickness Service to National Health Service

Are the facilities we have to e.g. NUH, fit for purpose when it was built in the 1970's
Patients with long term conditions not supported

Son with MH difficulties, left home in 40's
For most they left home in 20's as parents couldn't cope
Found out from a support group that people with LDs have right to a one hour health check.
Last April all MH team had left. They got more to work privately.

Staff in NUH all had hand held computers to access all records at bed side (in resus not wards)

Patient centredness – this is about caring
Carer support needed
Care not joined up and moving from one part of the system to another is difficult.
Feel that have been transacted, not cared for. Care can feel like a trick list
Appointment system at QMC feels very disjointed
As a patient, should understand it
Appointment letters arrive late ir don't arrive
Told don't understand process
Needed to go through a CCG process
Why is it by post? And 2nd class
Can't a text be sent
Wastes appointments
Had MRI appointment, missed it by 2 days as letter not received
Received a letter to phone up to make an appointment, but told had to be written to with appointment.

Vitamin B injection. NICE says every 2-3 months. Nurse says only every 3 months, but patient needs it more often to manage health.
Poor care

Who is going to take responsibility.

Table 5

Good experience:

Mainly healthy – Husband experience a few years ago. Went to Doctor with skin issue on leg. New service in place patient took a photo showed doctor and doctor wasn't sure so sent to daycase at Circle at issue was resolved. Prevented more complex issue i.e. cancer

Complex needs – friend has two conditions and needs a major operation. Getting two doctor's together is proving very difficult.

Emerging & complex needs – Wife had new hip four years ago, Social services provided adaptions and very positive experience. Recently went to GP with lump and referred quickly to hospital and had diagnostics. Confirmed as breast cancer. Negative due to have a falls nurse come to review. Once she knew cancelled appointment because she us having radiotherapy. Did not understand why needed to be referred back to GP. GP asks husband as carer at appointments if he is ok – positive experience.

Complex needs – Late husband died of cancer. Took a long time to diagnose. Referred on non-specific pathway and had repeated tests.

Complex needs – number of conditions. Patient found herself telling different specialists concerned of negative impact of new medication for one itc or the other itc.

Nobody showed patient at hospital how to do new inhaler. Told no money at hospital for trained staff to do this.

Emerging needs – Wanting GPs out of hours – nursing homes sending patients to hospital because nobody available to make decisions at pace.

Mainly healthy / self care – Uncertainty about access to GPs at Christmas. Communication needs to be improved so people know what is open and available. Information not well advertised, messages about prevention medicine really important i.e. pharmacy first to catch illnesses early / quickly. Education about services needs improving.

Idea to advertise with local news opening hours clearly promoted.

Healthwatch questions of the month – Christmas opening hours – most people poor understanding GP opening didn't filter through.

Fear of older people if they can't access a GP.
People reassured by telecare service. Lots of people not aware of modern technology and how to use it.

Isolated patients not receiving messages.

3 principles – principle of how do they link with social care: joined up care
Principle about holistic care

Table 6

Carer – some things / services useful but others quite the opposite. Now established carer, service = good. OT / psycho communicate with each other
Issue = accessing this carer

- Customer service on help lines – unhelpful
- Long assessments over the phone to be told not eligible for an assessment – felt as though screened out
- Generic county council call centre – perhaps if integrated will be more specialised rather than one size fits all BUT still limited resources, feel illusionary that integration will solve this.
- Not all carers are literate and educated to access care so many older people don't have ability and access these cannot.
- Initially GP would be first port of call now due to changes in role reliant on technology.
- Feel like patients asked to make decisions that there not informed on – need more information.

Very complex
Terminal, fastly degenerative disease. Felt like service was reactive rather than proactive. Care / decisions made a month after they should have been
EOL what matters most? Knowing who to go to?
Registered at health centre as a carer, then contacted by 'carer hub' – wealth of info sent, excellent and proactive. Very important and incredibly helpful – opposite of Council.
Communication = issue and key
Information that is understood, accessible to all demographics and specific.
Direct pathways rather than fragmented.
I work as a carer (Privately) integration of these key
Patient trying to maintain independence – element of pride 'yes I can'
Need tools to be proactive rather than reactive
Carers know who to escalate issues too
Holistic approach works, main issue are with fragmented acre
I work in MH practice, all services are in one place BUT cannot provide community care in reach due to resources – patients are being missed – organisational barriers.
Concerned by Centene input.

Table 7

3 main aims

Support people to stay well and independent
Provide care close to home wherever possible
Ensure people are only on hospital when that is the right place for their care

Group Discussion

Is it City and County Council who are involved with this work?

Used to be a lot more LA homes, home helpers. Health was community. We have seen a reduction in how money is spent to help people in their homes, when people need it?

Why are we using an American corporate model rather than a community based model like in Scandinavian countries?
Learning from other countries no just US e.g. NZ, Spain

Patronising to think that care is when everything is handed to you rather than self-care
You have to go through a very long process to prove you need support and then to actually getting it. It can be years.

What steps are you going through in terms of transformation? What are you measuring? Nobody is doing anything with the data.
Are they validated / reliable?
Focus on healthy life expectancy

Need a strategy to tackle poverty. STP should look at community development in the last 30 years.
Are we looking at the most deprived areas? Lots of projects that are written up. The STP is not looking at them.
'Opportunity Nottingham'
Maximise value of spend
Housing is part of the STP

Has there been a stakeholder discussion from all local groups to get an agreement on outcomes and how they are to be measured.
S Leaders in all key organisations working on this and communicating within their organisations
Signs of people working constructively across organisations
Challenge of getting people out of hospital is being addressed
Different systems for each locality for discharge 2 years ago. Now better integrated discharge
Hospital – bowl cancer treatment, even though it is not financially beneficial to the hospital

Should have gone to community based system when community care was first mentioned. We would be in a much better position nw. System would be more sustainable now if it had been done properly before.
2 year waiting list for orthopaedic surgery
Infrastructure around technology

Delay has led to money becoming very tight

Ageing men's and women's group members. Publications on what they can do.
Should be provision in the STP where healthy retired people can look after unhealthy
Left to charities/neighbours to help out. Should be provision within the STP to support volunteers / community provision.
University students would like to get involved in community work.
Getting volunteers is very difficult even with support and training. The need should be identified to the correct population.

System is too slow to respond to a citizen/carer.

Care organisations can't be sustained due to low wages. Cuts in private care as well as public.

Social care should be provided by the state.

Case study
Self funder had to stop as they were subsidising the LA £16 / hour

No guidance on how to use allocated budget given by LA. 5% on personalised health budget. Number will rise unless we help.
Concern around home care provider / training. Both quality and stability.

Key discussion topics

1. Provision of community services/voluntary sector – maximising social capital.
2. Timelessness of response by system to patients/carers
3. Home care – quality/sustainability

Table 8

Diagram over 4 areas make sense know anyone who fits
Makes sense, would make complicated MH covers 4 different areas – frequent flyers – varied, cannot put into area
More of MH in emerging needs and emerging needs into complex needs
Example – 2 LTC's not difficult but others may be more complex
Too simple to use in real world, but need to start somewhere.
In perspective may be more complex and chaotic with LTC interlinked.

Who is classifying? Very important – patient / health service
Diabetics may describe as mainly healthy
Somking pt

Target services complex / very complex – but need to share resources over other areas to support people around prevention to reduce them moving upwards in pyramid.

Integration is key – people move horizontal as well as vertical.
e.g. flu vac's – hoe can AHSC support people to have flu jabs
Use of common language – patient/person /population/citizen

We often struggle to refer to people / patients.
Patient centred care – I am a person
Individual – support around individual

Benefits on slide – benefits the provider services not recipients of service
People can quickly move up triangle
Preventability – 3 areas how is that used in language in the H&WB strategy
Doesn't always follow suit with services

People need to know it's about services / them to understand the involvement

How do we target services (money) across trainge – most probably goes on complex / very complex. Traditional HC is reactive Need to engage people in own health – creative.
What is a health need, what is a social care need – lots of overlap

Individual NOT systems
Keep proactivating, better than reactive

Example – Has 2 LTC
Not good use of resources
We use NHS resources without really reading, understanding

Continuing Care – example (out of area)
Lots of need but wasn't assessed as needing – didn't fit into category.

System is fragmented and complex – EOL (example) Notts
Never given any info about appropriate care, how it would be managed
In crisis route that couldn't set out of
When at EOL lots of missed info as changes all the time.

Look at patients and other service in society
Understanding level of ability
3 key principles amend/all
Terminology – support sounds like someone doing with
Support / inform enable
Enable patients to take control / self care
Voluntary sector – does active things – they help people to stay well in the community
How are we going to support the voluntary sector?

Supporting to stay well – on triangle / prior to triangle?

Accessibility / availability – all
Important no 2 services close to home, best care in place, on what basis is this assessed?
Services in community – liaison service
Rural
We need to do something
Need to be careful what we do
Learn lessons from past what works or not
What could be improved?
Prevention – Public Health awareness of social care
Level of Education
Money needs to be allocated well

About environment, education – Gov policy
Reduce choice
Where does PH sit? In LA in Notts ASCH

Right place right care (care closer to home)
Principle hospital – use other places
Hospital large focus as cost

Person centred – in principles
Case management – shared knowledge

Provide care in the right place for the individual wherever possible