



**WE ARE  
MACMILLAN.  
CANCER SUPPORT**



**Northern Cancer Alliance  
The Importance of Public Involvement  
Learn & Share Event**

**14<sup>th</sup> March 2019**

Collaborating to improve cancer care



# The Northern Cancer Alliance Commitment to Public Involvement

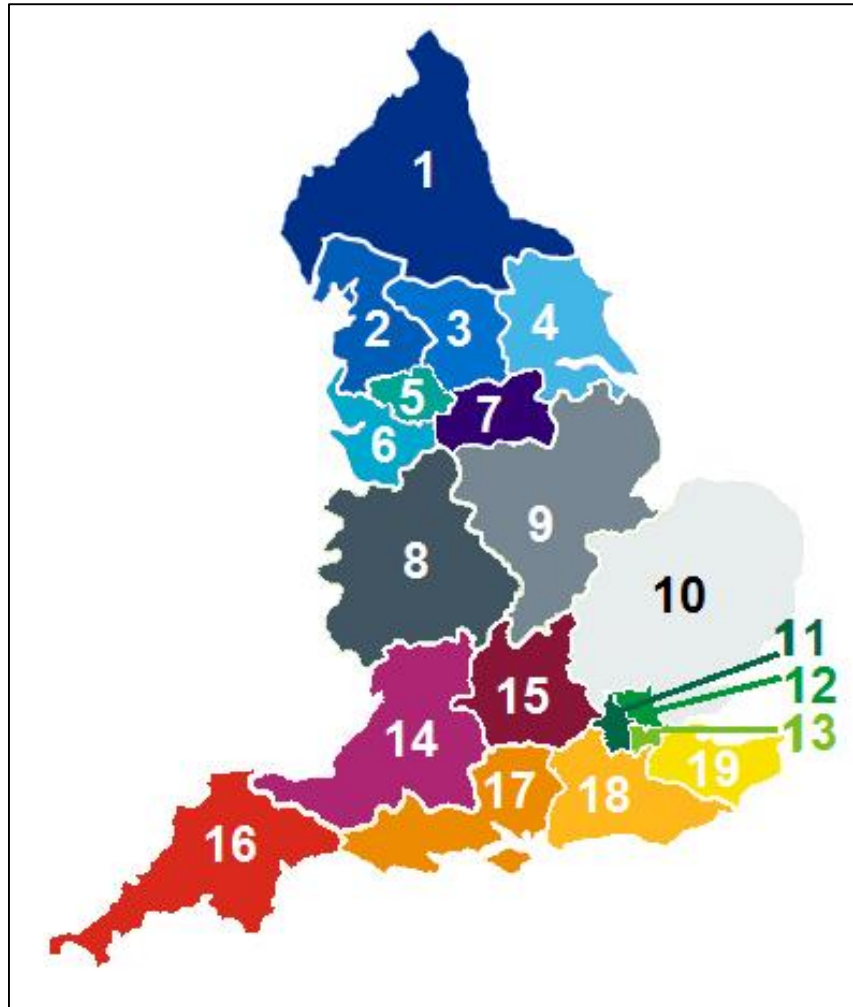
Alison Featherstone – Northern Cancer Alliance Manager

14<sup>th</sup> March 2019

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# What is a Cancer Alliance?

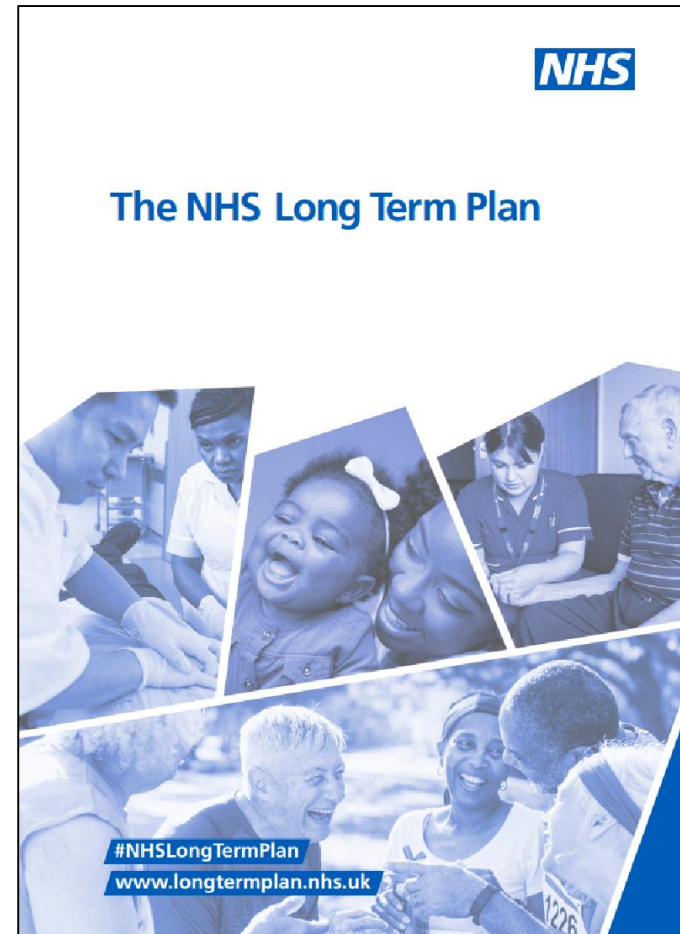
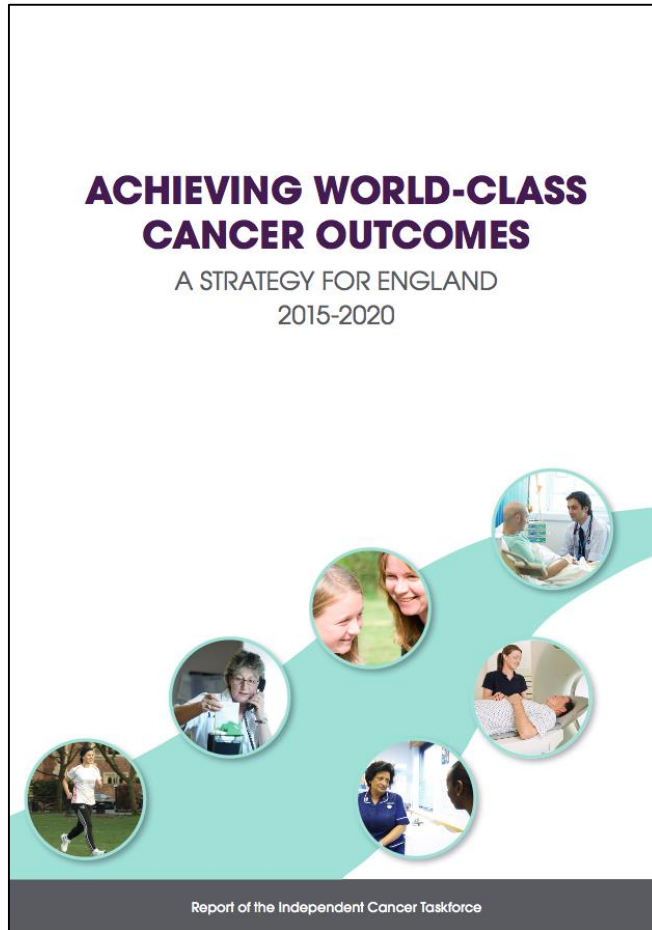


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**Northern**  
Cancer Alliance

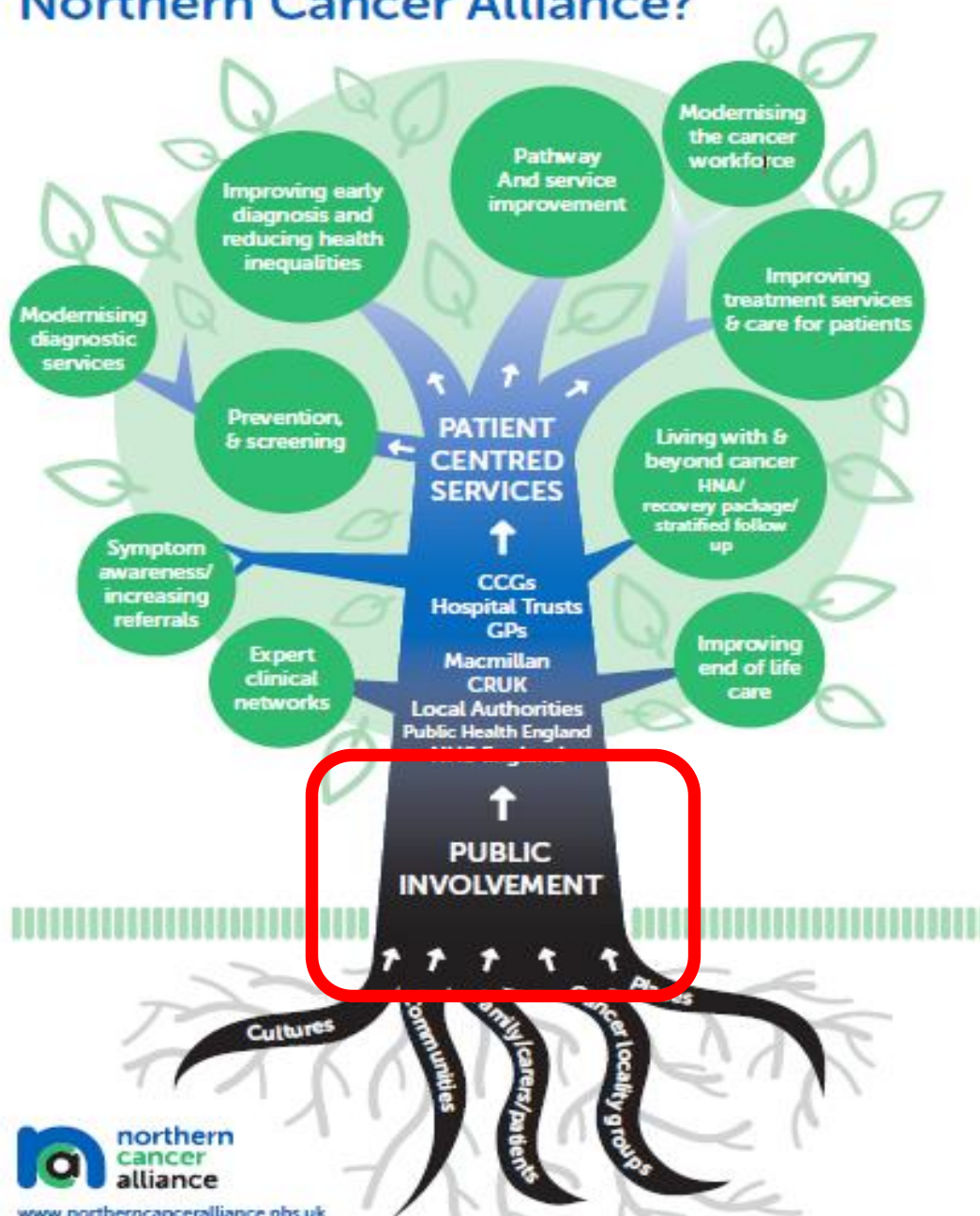
# Informing our work plan



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# What is our Northern Cancer Alliance?



# Involvement is no longer a “nice to do”

*All the evidence points the same way: that working in partnership with people and communities leads to better health, better outcomes and better use of the money.*

*Whether it is shared decision making in the GP surgery, multidisciplinary team working in the hospital, or co-designing services with the public, involving people is not a ‘nice to do’, it is a ‘must do’.*

*Patients, carers and the public can help. They can help busy and overstretched managers and clinicians grappling with the need to ‘transform’ and ‘sustain’ NHS and social care services.*

*Engagement and involvement is no longer something organisations can delegate to their ‘patient engagement lead’; this is core business.*



Jeremy Taylor, Chair of the People and Communities Board and Chief Executive of National Voices

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**Northern  
Cancer Alliance**

# Improving cancer outcomes

Involving people is essential to the successful achievement of the Alliance key priorities, these include:

**Prevention and screening** – consult with communities to understand attitudes and beliefs. Work in partnership to develop approaches that motivate people to adopt healthy lifestyles and engage with screening services.

**Reduce health inequalities** – work in partnership with communities to develop approaches and services that engage and support those at greatest risk.

**Improve early diagnosis** – consult and work in partnership with communities to develop initiatives for information sharing and awareness raising.

**Improvement of treatment services** – work in partnership with patients to understand their experiences of care and treatment, co design services that are centred around the needs of the individual and their families.



# Our Commitment

- The Alliance recognises the value of meaningful involvement and understands the interdependency between patient safety, clinical effectiveness and the patient experience within healthcare.
- We are fully committed to the involvement of the public in all aspects of our work and the development of a culture in which involvement becomes part of our “usual business”.
- We believe that involvement should be the responsibility of everyone and not that of a named individual or team.
- To achieve this vision for involvement across the Alliance we have embarked on a two year Macmillan funded project. This important piece of work has produced a framework for involvement which will support the further development of our approach now and into the future.



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WE SPEND A LOT OF TIME  
DESIGNING THE BRIDGE,  
BUT NOT ENOUGH TIME  
THINKING ABOUT THE PEOPLE  
WHO ARE CROSSING IT.

- DR. PRABHJOT SINGH

*Thank you*



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# Developing a Framework for Public Involvement

## The Northern Cancer Alliance Approach

Members of the project steering group

14<sup>th</sup> March 2019

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# Setting the scene

- The Northern Cancer Alliance is fully committed to involve the public in all aspects of their work.
- The Alliance already had Patient & Public Voice and Lay Representatives at key meetings and committees.
- There was a realisation that involvement needed to move beyond the current activities to one which involved all levels of the system.
- Macmillan supported this vision of integrated involvement by providing funding for a two year project project to develop a sustainable framework for involvement.



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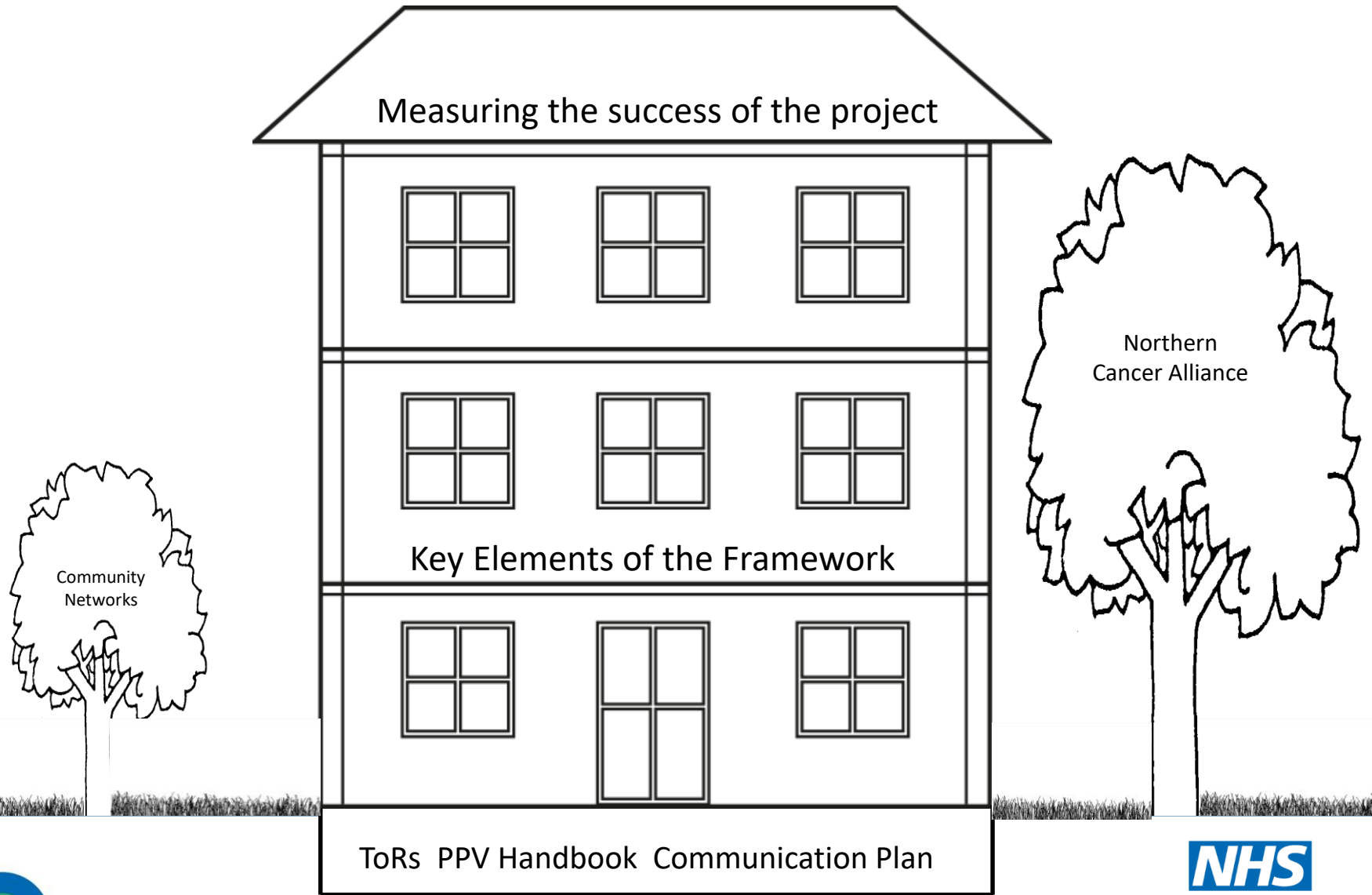
# Aim of the project

- Develop a framework for public involvement that would support an Alliance system where public involvement is “usual business” and the responsibility of everyone not a specific team or individual.
- Develop a collaborative approach which supports effective involvement with the right people at the right time.
- Develop a common language for involvement activities that is accessible to all.
- Develop approaches and tools that support involvement at all levels of the Alliance work plan.



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# Articulating our approach



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# Simplifying the language we use

Public Involvement:

*“Public” describes everyone living in the Alliance area affected or potentially affected, by cancer.*

*“Involvement” describes any partnership activities with the public to improve cancer outcomes and services.*



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# Understanding what is important

We identified three groups of people we needed to speak to:

1. Members of the public including patients, families and carers.
2. Community Partners i.e. Healthwatch , voluntary organisations and charitable organisations.
3. Members of the Alliance support team at Waterfront 4.



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# Themes from the public

- Accessible information (written & verbal)
- Development of confidence and skills for involvement
- Timely feedback and responses
- Opportunities (awareness of, and accessible)
- Commitment (time and sign-up of professionals)
- Meaningful
- Transparency
- Listening and feeling listen to
- Feeling valued
- Supportive and confidence building
- Professional attitudes
- Right environments i.e. community groups
- Ensure you involve the “right people”.
- Timeliness of activities
- Inclusive to all
- Variety of methods to get involved
- Consideration of barriers e.g. travel, size of group
- Understanding what we have already told you i.e. experience data



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# Themes from community partners

- A two-way approach between the Alliance and partners to sharing information.
- Sharing good practice, news and events from across the Alliance communities.
- Understanding Alliance priorities and involvement in key meetings.
- Promoting and supporting involvement activities on behalf of the Alliance.



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# Themes from the NCA support team

- Strong commitment needed from everyone.
- Development of the involvement knowledge and skills.
- Access to appropriate tools and approaches.
- Ability to connect with the “right” members of the public.
- Systems that support good involvement.



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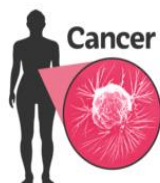


# Keeping people up to date with our progress

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**NHS**  
Northern  
Cancer Alliance

## Northern Cancer Voices



### Welcome to our newsletter!

We would like to tell you about a new project.

This project is looking at the best way of giving people an opportunity to get involved in developing and improving NHS cancer services.

We have formed a project group who meet every couple of months to talk about how we can do this.

### Congratulations to Kirsty!

Massive congratulations to Kirsty who is a member of our project steering group. Kirsty is a winner of the first Learning Disability and Autism Leaders' List.

This is a national award and organisers received nearly 600 nominations! We are all extremely proud of Kirsty and very grateful for her contribution to the project.



### Do you have something to say?



We would like to tell people about groups and events for people affected by cancer. Please get in touch if you would like to tell us about your group or event.









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**NHS**  
Northern  
Cancer Alliance

# Using language everyone understands

jargon



|   |  |   |
|---|--|---|
|    | <b>Northern Cancer Voices Project</b>  |  |
| <p>This project is looking at the best way of giving people an opportunity to get involved in developing and improving NHS cancer services.</p> <p>We would like speak to people to understand the best way to involve them. Thank you for helping us to do this by answering the questions in this survey.</p> |  |   |
|    | <p>Do you feel it is important for you to have a say about NHS cancer services?</p> <p>Please give a reason for your answer.</p> |   |
|    | <p>Has anyone ever asked you about NHS cancer services? Or any other NHS services?</p>   |   |
|    | <p>What would make it easier for you to have your say?</p>   |   |
|   | <p>Is there anything that might stop you having your say?</p>  |   |
| <p>If you would like to return your completed survey to us by email, please send to <a href="mailto:Joannemackintosh@nhs.net">Joannemackintosh@nhs.net</a></p>  |  |   |



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# Partnerships



Darlington. The network is free to attend and open to all. Please find agenda attached below. Food For Thought Darlington would be very grateful if people...

[Read in browser »](#)



## Northern Cancer Voices e-bulletin

Body:

Please find attached below the latest edition of the Northern Cancer Voices e-bulletin which contains project updates and news about cancer services.

[Read in browser »](#)



[A message from Darlington Citizens Advice Bureau - Living](#)



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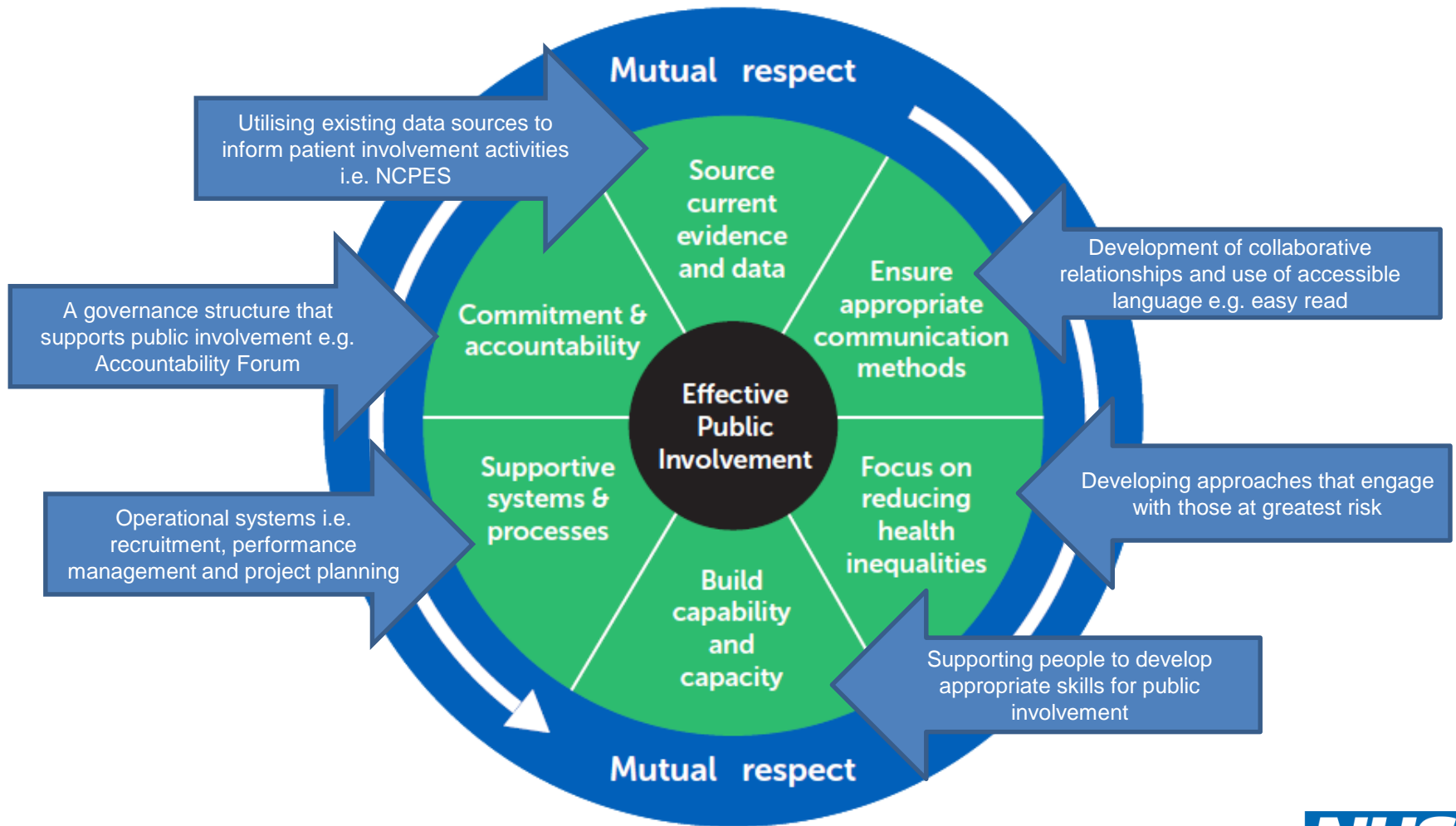


# Co-designing the Framework



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# NCA Framework for Public Involvement



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Northern  
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# Project Work Stream Groups

**Commitment &  
Accountability**

**Human  
Resource**

**Communication**

**Systems  
&  
Tools**



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# Work Stream Group Actions

| Commitment & Accountability   | Human Resource  | Systems & Processes  | Communication  |
|---|---|--|--|
| <p>Review PPV membership of key Alliance groups and meetings.</p> <p>Evaluate the Lay Representative role.</p> <p>Introduce an accountability forum to the governance structure of the NCA.</p> <p>Review NCA values for their links with public involvement.</p> | <p>Produce role descriptors to support PPV activities.</p> <p>Integrate public involvement values into NCA recruitment process including JD's, vacancy adverts and interview questions.</p> <p>Integrate public involvement values, awareness and training into NCA staff induction.</p> <p>Investigate possibilities with NHSE for the integration of public involvement values into appraisal process.</p> <p>Identify public involvement training and support to facilitate NCA activities.</p> <p>Investigate possibilities of peer support from cancer patient &amp; carer groups.</p> | <p>Develop an involvement assessment tool to be sited within the NCA project plan template.</p> <p>Develop an patient experiential pathway mapping tool.</p> <p>Develop a NCA report template that includes a public involvement activity section.</p> | <p>Develop the NCA public involvement website pages to support information sharing i.e. best practice, NCA plans etc.</p> <p>Produce a directory of community partners</p> <p>Develop channels for feeding information in from community organisations e.g. Healthwatch.</p> <p>Develop criteria for producing accessible information that supports public involvement activities.</p> |



*Thank you for listening any questions*

WE SPEND A LOT OF TIME  
DESIGNING THE BRIDGE,  
BUT NOT ENOUGH TIME  
THINKING ABOUT THE PEOPLE  
WHO ARE CROSSING IT.

- DR. PRABHJOT SINGH



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# National Cancer Programme

Engaging People &  
Communities

14 March 2019





## Cancer survival is the highest ever

8,500 more survived their cancer (2015 figures) for at least one year than would have been the case four years before



Quality of life metric tested in five Cancer Alliances



Overall patients rate their cancer care 8.8 out of ten – the best results ever



Over 1.7 million people urgently referred by their GP – half a million more than before NG12.



£130 million Radiotherapy modernisation programme – largest in 15 years



Six new molecular diagnostic tests funded by the NHS



10 new multi-disciplinary 'one stop shops' – faster diagnosis and better patient experience



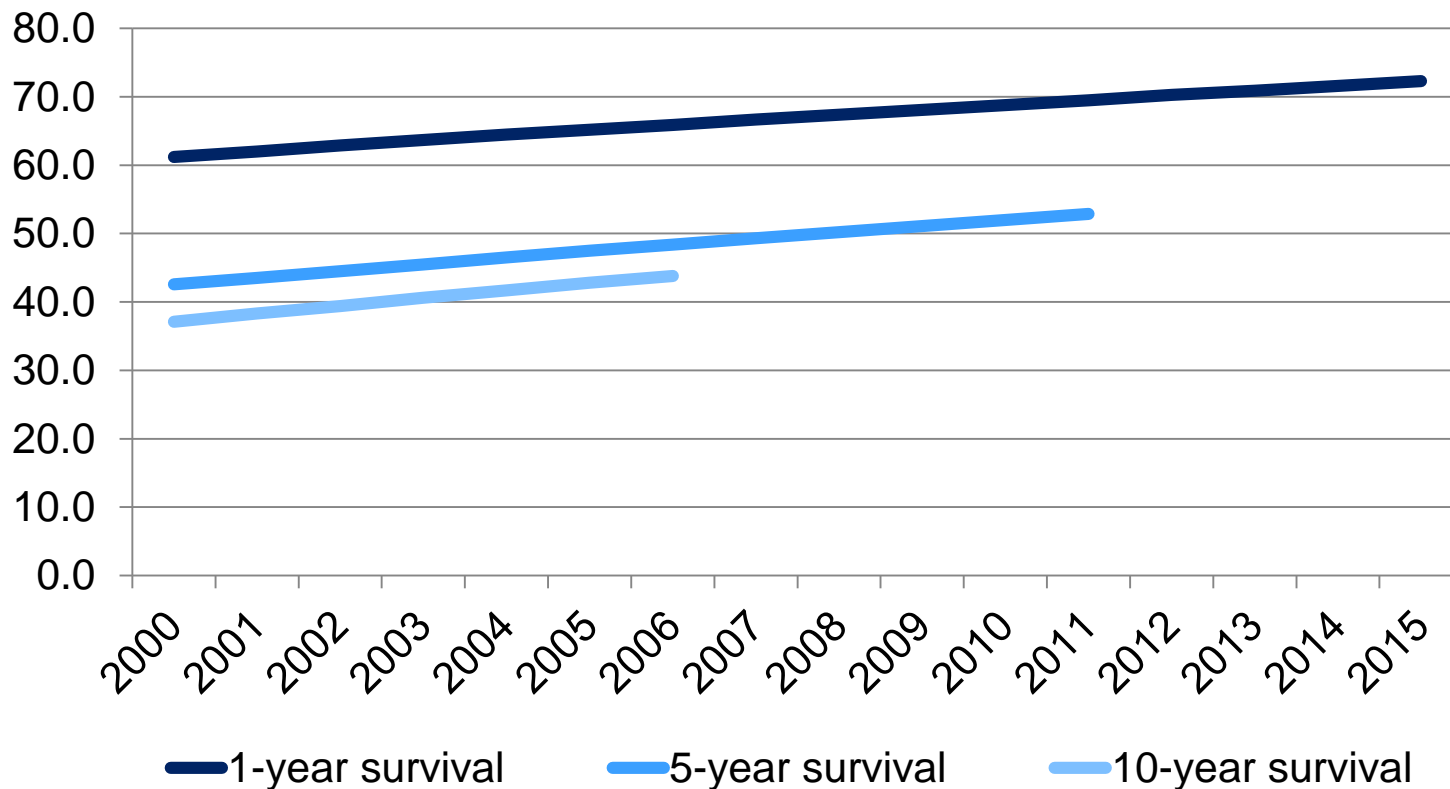
First Proton Beam patients seen in December 2018



Over £200 million distributed through Cancer Alliances over 2 years

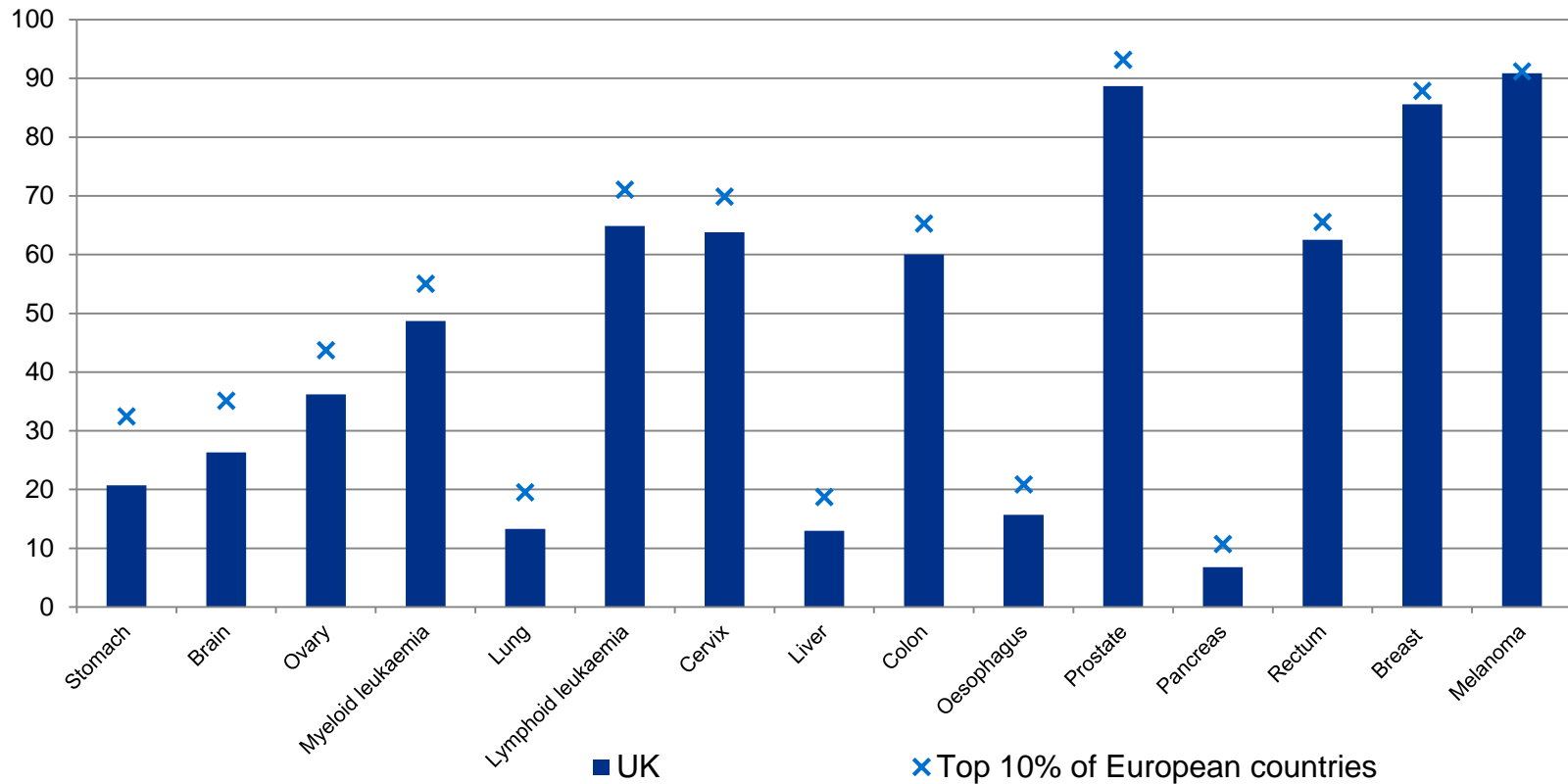
# More people are surviving

All-cancer survival, 2000 -2015, ONS



# But there's more to do....

Estimated 5-year survival in the UK and the 10% leading European countries (CONCORD, 2010-2014)



# The Long Term Plan ambition

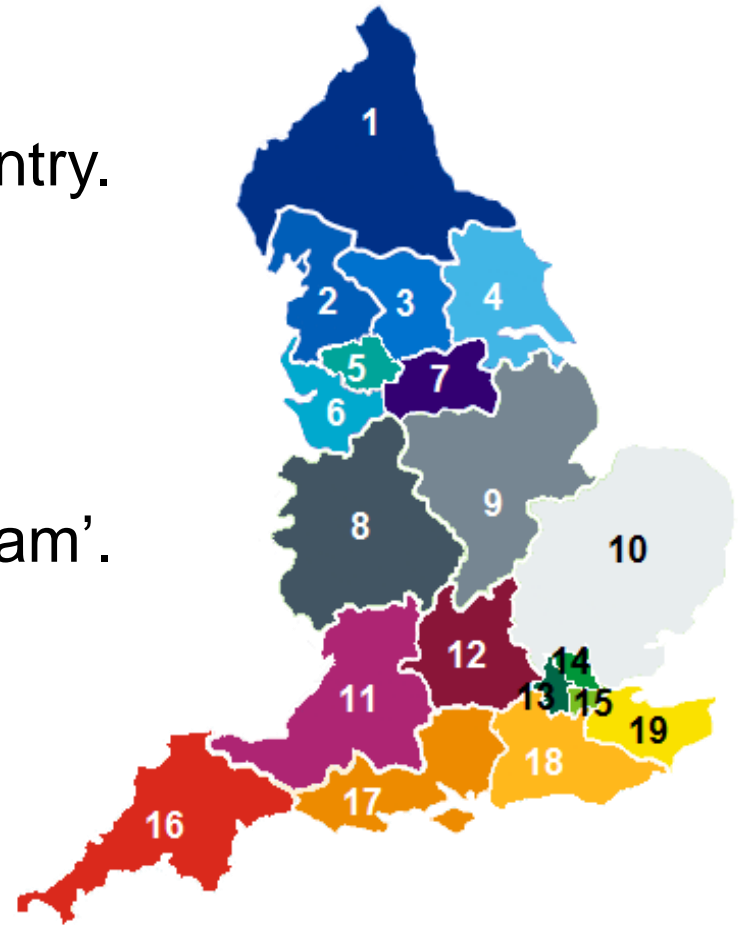
We will continue to transform cancer care so that from 2028:

- an extra 55,000 people each year will survive for five years or more following their cancer diagnosis; and
- three in four cancers (75%) will be diagnosed at an early stage.



# Cancer Alliances

- 19 Cancer Alliances leading transformation across the country.
- Working with Integrated Care Systems (ICS) and System Transformation Partnerships (STPs) – the ‘cancer workstream’.
- ‘Go to’ for innovation and best practice.



[http://bit.ly/Cancer\\_Alliance\\_Map](http://bit.ly/Cancer_Alliance_Map)



# Supporting Alliances

- **Leadership** – the authority and influence to lead delivery across their geographies including on 62d performance
- **STP and ICS relationships** – clearly defining the role of the Alliance in working with their STPs/ICSs
- **Geographies** – reviewing where boundaries need to change to enable Alliances in performance and transformation
- **Data and evidence** – a greater focus on using whole pathway data, analysis and evidence to drive delivery and transformation activities
- **System capability** – strengthening Alliances' capability to improve patient experience and expand engagement.



**Between April and July last year we carried out research on Alliance's engagement and held a workshop in August 2018**



# The workshop created consensus on themes for further work

1. Short-term programme funding and lack of dedicated resource
2. Need for central standards and frameworks
3. Measuring impact of engagement
4. Making engagement business as usual
5. Training and support for patient and public voice representatives
6. Finding ways to capture wider patient experience and support needs
7. Flexible and creative involvement methods to reach diverse groups who experience poorer outcomes



# In response

- We created:
  - An online workspace for patient and public engagement with toolkits, good practice guides, and research.
  - A forum and other networking resources.
- In addition, we organised a series of 3 Share & Learn group discussions on:
  - Measuring the impacts of engagement
  - Reaching diverse groups who experience poorer outcomes
  - Making engagement business as usual



# Thanks, and please stay in touch

## **Bulletins:**

Cancer Stakeholder:

[bit.ly/NHS\\_Cancer\\_Programme\\_Bulletin](https://bit.ly/NHS_Cancer_Programme_Bulletin)

# building a caring future

HOSPITAL | COMMUNITY | HOME

Measuring and improving patient experience  
Annie Laverty NCA Public Involvement Event

# Number of staff believing high quality patient care is the No1 priority of the trust.



*“You cannot make things happen, but you can create a space in which what you want is more likely to happen.”*

– Chinese proverb

# Shine a spotlight on interactions.

*“At times in medicine you feel you are inside a colossal and impossibly complex machine whose gears will turn according to their own arbitrary rhythm.*

*The notion that human caring, the effort to do better for people, might make a difference can seem hopelessly naive.*

*But it isn't...”*

- Gwande 2008



# Our focus on measurement.

- Timely
- Owned
- Actionable
- Specific
- Talked about



# Looking after your workforce



# Ambition

- To improve patients' (and families') experience of care in hospital
- To support staff to provide the sort of care they would like for themselves and their families

**#1.**

Leadership **at all levels** focused on  
compassionate care and  
service improvement

# Coherence, creativity and contact



Compassionate care is not only good for patients – it nourishes the care giver too

# #2.

Use insights from patients and families to  
**improve care**



# Responding to patient feedback

- Feedback from more than 50,000 people every year
- Measuring what matters most to patients in a variety of ways and at different points of care
- Right time' data giving site, specialty, and individual consultant data, externally validated to feed through appraisal system
- Real time measurement fed back to clinical teams within 6 hours



# Health Quality Checkers Team



## The Good Health for all Standards

**These are the standards we will use to check your service**

- I am **involved** in my care at all times.
- My care, treatment and support is **planned** to meet my needs.
- I get good care and feel **safe**.
- I get good care from staff who are **trained** and know how to do their job well.
- I get care from a service which carries out **regular** checks to make sure they are doing a good job.

# Inviting older people onto our wards



*“Compassion is the ability to see what needs doing right now and the willingness to do it right now “*

– Brad Warner

# #3.

Be **open and honest** with patients,  
families and the public

# Transparency

Be open and honest about current state, expectations, and actions needed for improvement.

If you're going to be naked it's good to be buff.



# Our Voice...

## What our patients say

View the results

# Your voice...

This is what you told us about our consultants through our out-patient survey. We are using this valuable feedback to continuously improve the quality of our service and the care you receive.

## Consultant patient satisfaction top 20

6538 patients surveyed

Survey covered 137 consultants  
Highest score = 98.29% Lowest score = 79.52%

Average satisfaction rate across all 137 consultants  
**93.01%**

How our consultants compare against the rest of the country...

- NHS average = 86.86%
- NHS top 20% = 89.14%
- Best NHS trust score = 94.57%

|                      |        |
|----------------------|--------|
| 1. Simpson E.E.      | 98.29% |
| 2. Wells R.H.        | 97.88% |
| 3. Dewar M.S.        | 97.36% |
| 4. Thomson R.K.      | 97.16% |
| 5. Mills S.          | 97.06% |
| 6. Yousef M.M.K.I.   | 97.04% |
| 7. Wood B.H.         | 96.90% |
| 8. Lee A.F.          | 96.87% |
| 9. Lewis-Rosend N.J. | 96.81% |
| 10. Tippley C.       | 96.79% |
| 11. Cooper D.        | 96.60% |
| 12. Woods D.R.       | 96.46% |
| 13. Davison P.M.     | 96.42% |
| 14. Patel E.T.       | 96.41% |
| 15. McKenna P.       | 96.35% |
| 16. Carr M.          | 96.06% |
| 17. Mathava S.       | 95.81% |
| 18. Powell J.        | 95.88% |
| 19. Morris D.        | 95.87% |
| 20. Bhagwat A.R.     | 95.48% |

Northumbria Healthcare NHS Foundation Trust

# Your voice...

What you told us about our outpatient services through our patient survey and how each of our hospitals performed

## What you told us about our DOCTORS

4819 respondents

Did you have enough time to discuss your health or medical problem with the doctor?  
93.86% 93.00% 94.44% 93.33% 94.00% 96.72% 92.35% 100.00% 92.65% 94.83%

Did the doctor seem aware of your medical history?  
93.63% 91.81% 95.24% 96.67% 93.40% 93.08% 92.11% 100.00% 94.07% 94.22%

Did the doctor listen to what you had to say?  
92.83% 95.47% 96.50% 100.00% 96.33% 97.01% 95.10% 92.86% 95.30% 95.82%

If you had important questions to ask the doctor, did you get answers that you could understand?  
86.30% 91.67% 89.32% 86.21% 92.88% 89.34% 89.38% 91.67% 91.05% 89.76%

Did the doctor explain the reasons for any treatment or action in a way you could understand?  
90.48% 94.47% 91.39% 96.55% 95.18% 90.51% 92.00% 100.00% 93.58% 93.84%

Did you have confidence and trust in the doctor examining and treating you?  
92.72% 94.47% 95.14% 100.00% 96.73% 95.51% 95.00% 100.00% 96.37% 96.58%

Would you recommend our services to your family and friends?

Northumbria Healthcare NHS Foundation Trust

# Your voice...

What you told us about our outpatient services through our patient survey and how each of our hospitals performed

## What you told us about the DIGNITY OF CARE YOU RECEIVED

NHS average = 93% NHS top 20% = 95% NHS best = 97%

|                 |     |
|-----------------|-----|
| Almbeck         | 92% |
| Barnack         | 96% |
| Blyth           | 97% |
| Fresham         | 95% |
| Morpeth         | 98% |
| North Tyne-side | 96% |
| Wansbeck        | 96% |

Being addressed the way I want to be addressed. Being asked, not told. Having people working with me, respecting my choices, my decisions. And if I'm able to control my situation, being allowed to do that without being judged and being seen as difficult that is dignity.

Northumbria Healthcare NHS Foundation Trust

# Your voice...

This is what you told us about our services through our in-patient survey. We are using this valuable feedback to continuously improve the quality of our service and the care you receive.

## Ward 1 Blyth Community Hospital

89 patients between February and May 2011

39% - Kind, empathetic, caring staff  
23% - Co-ordinated efficient care  
19% - Personalised care  
11% - Cleanliness of the ward

8% - Quality of the food

I have been in two or three hospitals but this is the best one for me lately

Northumbria Healthcare NHS Foundation Trust

# Your voice...

'two minutes of your time' survey results

You give us two minutes of your time to tell us what you thought about the care you received in our hospitals across Northumbria...

33.3% - Kind, empathetic, caring staff  
19.7% - Quality of staff  
14.8% - Co-ordinated, efficient care  
4.5% - Professionalism  
4.7% - Quality of food  
2.9% - Cleanliness  
1.3% - Efficiency  
0.4% - Support of family  
0.4% - Leadership

The things that stood out most for you...

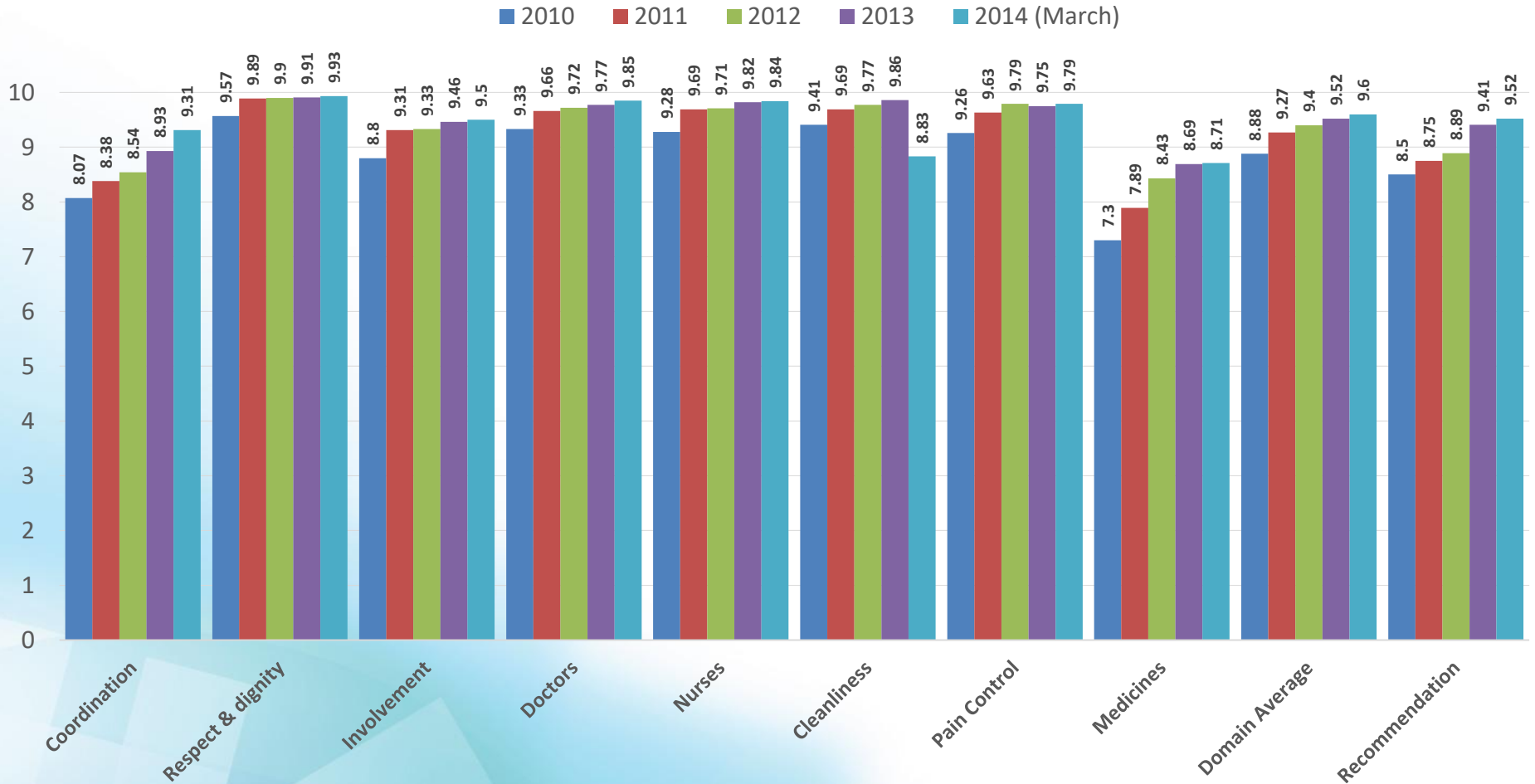
Northumbria Healthcare NHS Foundation Trust

**#4.**

**Measurable improvement and  
sustained staff engagement**

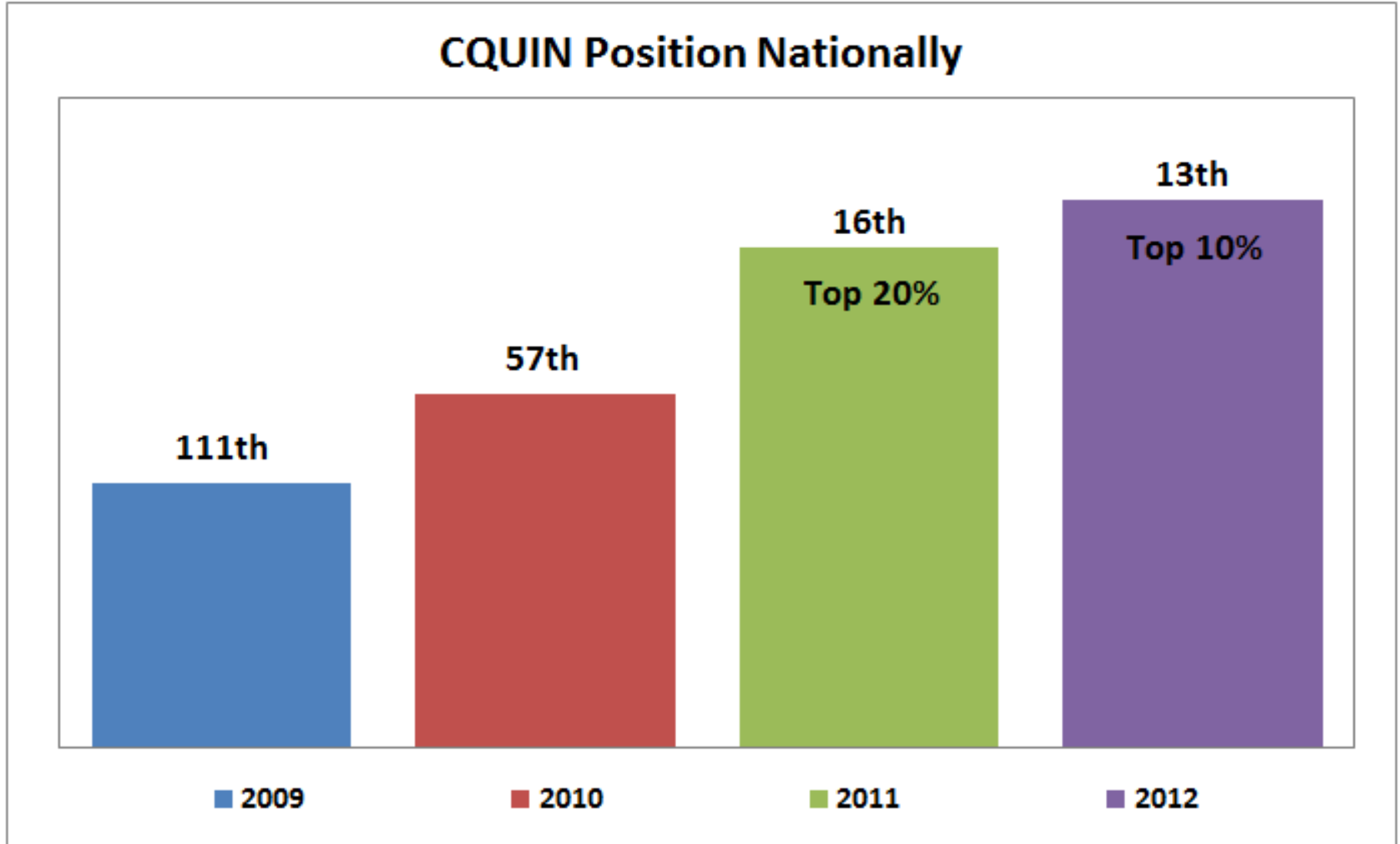
# Organisational level

# Real time improvements (n= 12,000)





# Commissioning for quality.



# CQC National Inpatient Survey

| Rank | Trust  | The Emergency / AE Department | Waiting List & planned admissions | Waiting to get to a bed on a ward | The hospital and ward | Doctors    | Nurses     | Care and treatment | Operations and Procedures | Leaving Hospital | Overall views of care & Services | Overall experience | Average Score |
|------|--|-------------------------------|-----------------------------------|-----------------------------------|-----------------------|------------|------------|--------------------|---------------------------|------------------|----------------------------------|--------------------|---------------|
| =1   | The Royal Marsden                                    | n/a                           | 9.5                               | 9.1                               | 9.0                   | 9.3        | 9.2        | 8.8                | 9.2                       | 8.4              | 6.8                              | 9.0                | 8.8           |
| =1   | Queen Victoria Hospital                              | n/a                           | 9.4                               | 9.1                               | 8.8                   | 9.4        | 9.4        | 8.9                | 8.9                       | 8.4              | 7.1                              | 8.9                | 8.8           |
| =1   | Liverpool Heart and Chest                            | n/a                           | 9.3                               | 9.6                               | 9.1                   | 9.5        | 9.4        | 8.9                | 8.8                       | 8                | 6.2                              | 9                  | 8.8           |
| =4   | The Clatterbridge Cancer Centre                      | n/a                           | 9.5                               | 9.6                               | 8.9                   | 9.3        | 8.9        | 8.7                | 8.6                       | 8.2              | 6.9                              | 8.7                | 8.7           |
| =4   | Papworth Hospital                                    | n/a                           | 9.2                               | 9.4                               | 8.9                   | 9.3        | 9.2        | 8.7                | 8.8                       | 8.2              | 6.4                              | 8.9                | 8.7           |
| =4   | The Christie   | n/a                           | 9.4                               | 8.7                               | 8.9                   | 9.3        | 9.2        | 8.7                | 9.2                       | 8.1              | 6.6                              | 8.9                | 8.7           |
| =4   | The Robert Jones and Agnes Hunt Orthopaedic Hospital | n/a                           | 8.9                               | 9.2                               | 9.1                   | 9.4        | 9.0        | 8.6                | 8.9                       | 8.0              | 6.4                              | 9.0                | 8.7           |
| =8   | Liverpool Women's                                    | n/a                           | 9.3                               | 8.9                               | n/a                   | 9.3        | 9.2        | 8.7                | 9                         | 7.8              | 6.3                              | 8.8                | 8.6           |
| =8   | The Royal Orthopaedic Hospital                       | n/a                           | 9.0                               | 8.7                               | 9.1                   | 9.3        | 9.0        | 8.5                | 8.8                       | 8.0              | 6.5                              | 8.7                | 8.6           |
| =10  | The Newcastle Upon Tyne Hospitals                    | 9.4                           | 9.2                               | 8.6                               | 8.7                   | 9.2        | 9.1        | 8.5                | 8.8                       | 7.7              | 5.9                              | 8.6                | 8.5           |
| =10  | <b>Northumbria</b>                                   | <b>9.2</b>                    | <b>9.1</b>                        | <b>8.7</b>                        | <b>8.8</b>            | <b>9.1</b> | <b>8.9</b> | <b>8.5</b>         | <b>8.7</b>                | <b>7.8</b>       | <b>5.9</b>                       | <b>8.5</b>         | <b>8.5</b>    |

Out of 149 Trusts, Northumbria is ranked joint 10

Site level

# According to 6575 patients interviewed

- Care more coordinated & consistent, with evidence of better team working
- More likely to involve patients in decisions
- Better relationships with doctors & our nurses – with patients reporting higher levels of trust
- Better at managing pain
- More likely to show kindness and compassion
- Overall rating of care has statistically changed for the better

# Through highly engaged staff...

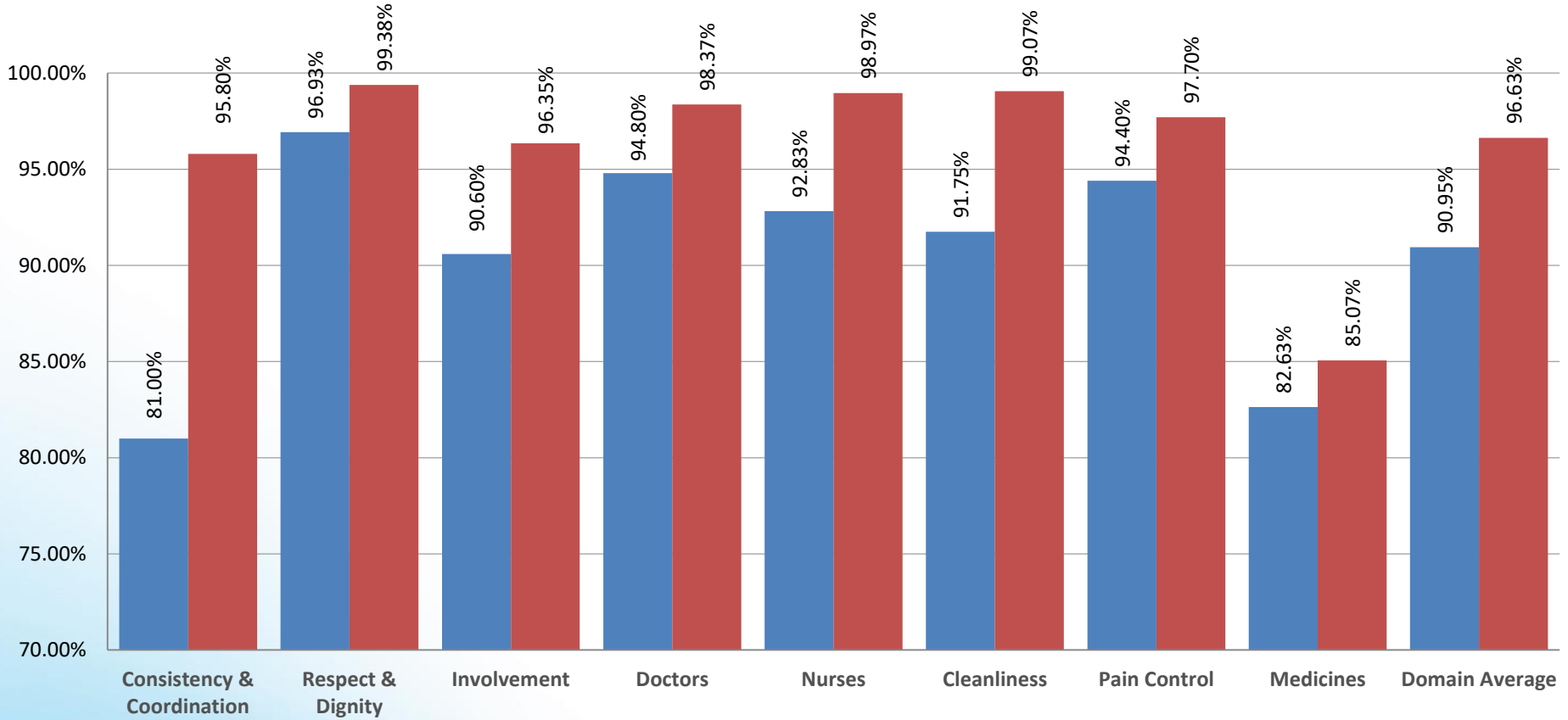


*“I like working for an organisation where I’m listened to, and allowed to make the changes we need to make care better for patients.”*

**94% of staff at Northumbria believe that their role makes a difference**

FOR HEALTHCARE LEADERS  
**HSJ** | **BEST PLACE TO WORK** | **2015 AWARDS**  
**Nursing Times**

# Ward level

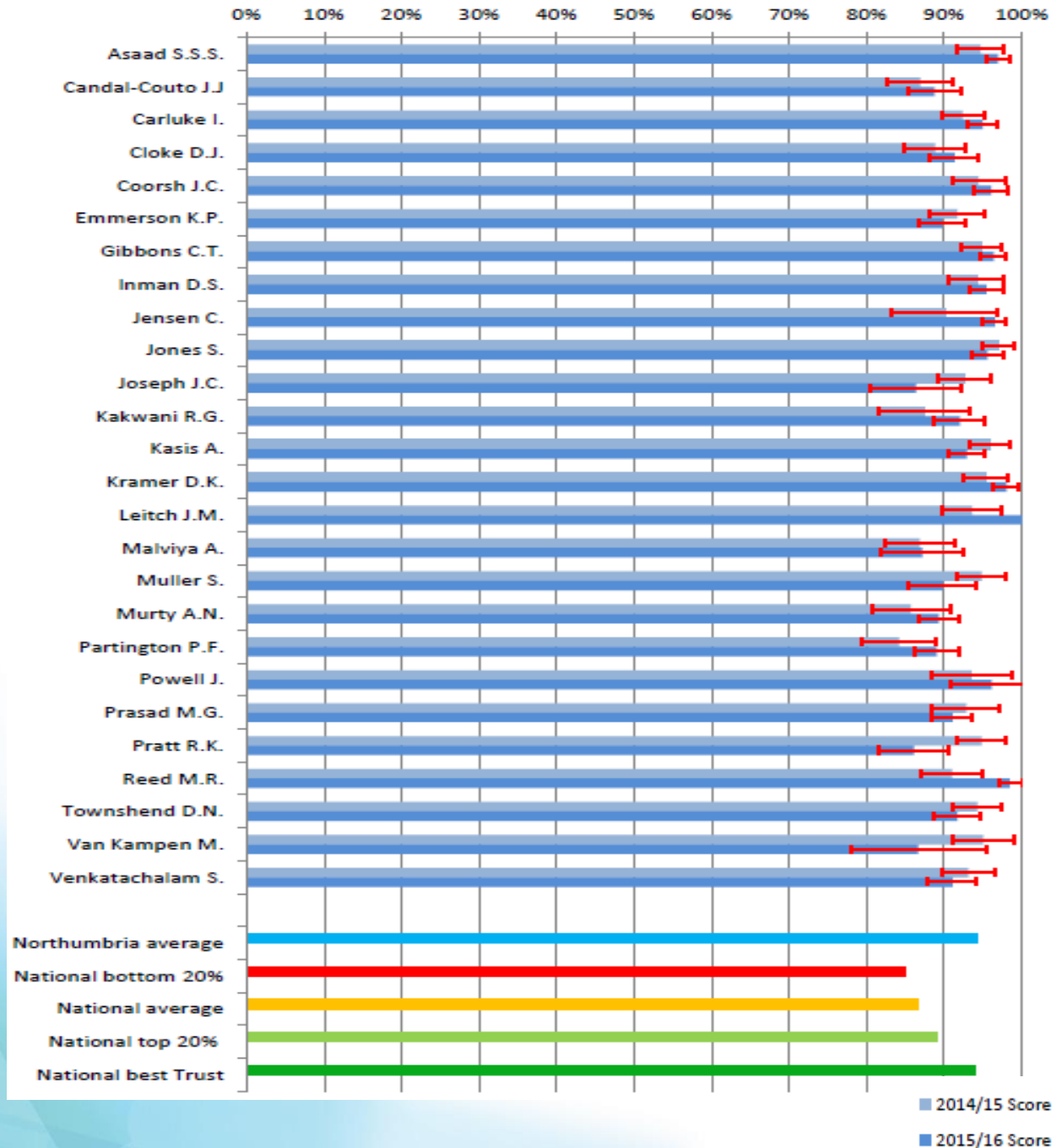


|                  | Consistency & Coordination | Respect & Dignity | Involvement  | Doctors      | Nurses       | Cleanliness  | Pain Control | Medicines    | Domain Average |
|------------------|----------------------------|-------------------|--------------|--------------|--------------|--------------|--------------|--------------|----------------|
|                  | 81.00%                     | 96.93%            | 90.60%       | 94.80%       | 92.83%       | 91.75%       | 94.40%       | 82.63%       | 90.95%         |
|                  | 95.80%                     | 99.38%            | 96.35%       | 98.37%       | 98.97%       | 99.07%       | 97.70%       | 85.07%       | 96.63%         |
| <b>Increase:</b> | <b>14.80%</b>              | <b>2.46%</b>      | <b>5.75%</b> | <b>3.57%</b> | <b>6.14%</b> | <b>7.32%</b> | <b>3.30%</b> | <b>2.43%</b> | <b>5.68%</b>   |

# Individual consultants

**ORTHOPAEDICS**  
**Outpatient Survey, to**  
**March 2016**

*Did you have enough time to discuss your health or medical problem with the doctor?*





# Learning from stories.



*“Emotion bonded with information becomes memorable, resonant and actionable.”*

Our care has been rated

**'OUTSTANDING'**

#OutstandingNHS



Northumbria Healthcare  
Overall rating

Outstanding 

“ *All staff treated patients with dignity and respected their privacy...* ”

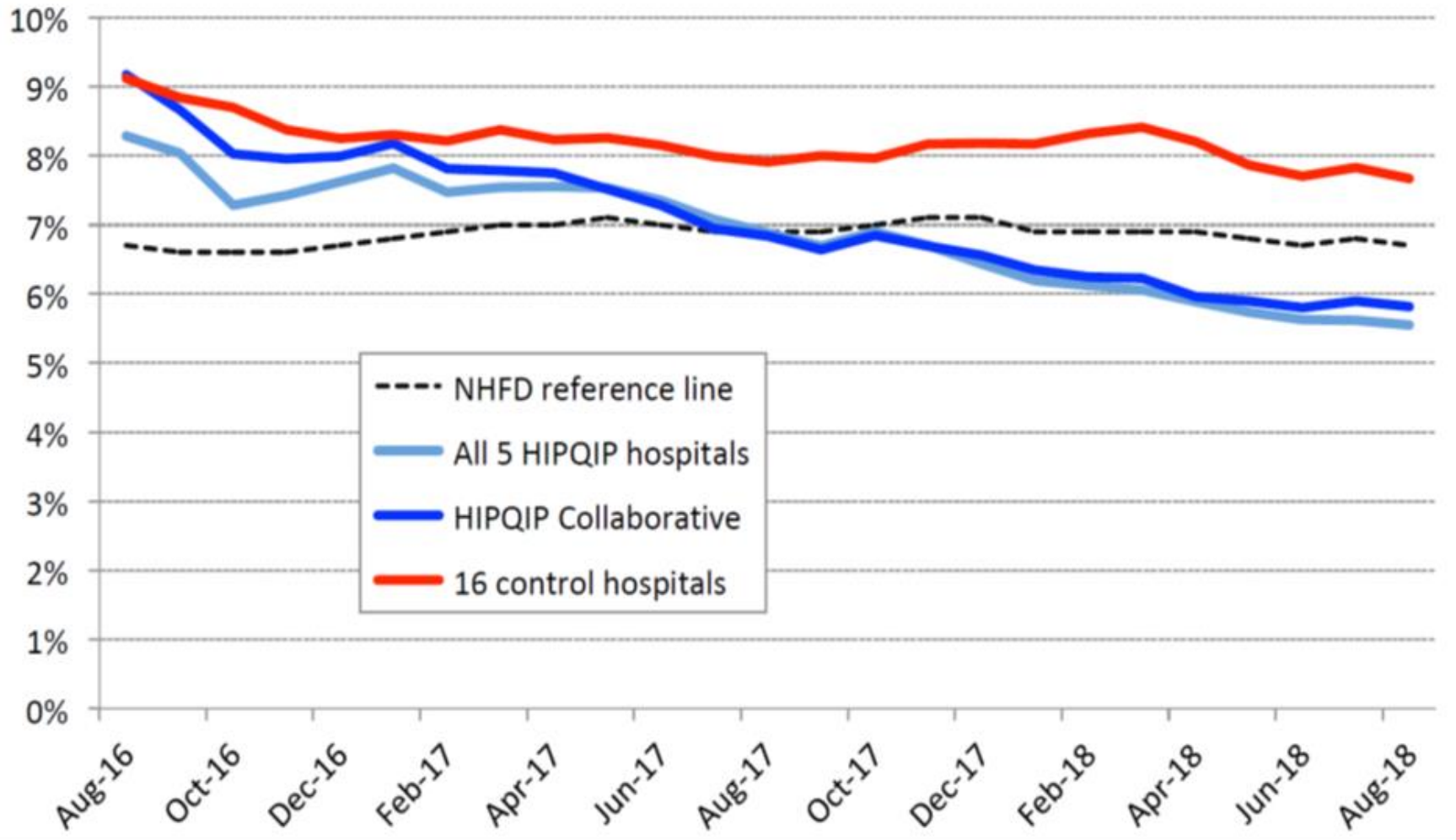
Inspected and rated

Outstanding 



# Scaling up improvement

# 119 lives saved



# HIP QIP

Northumbria Healthcare NHS Foundation Trust's HIP Quality Improvement Programme (known as HIP QIP) is an initiative to improve care for older people who've had a hip fracture.

Scaling Up Improvement Programme



Scaled up to six NHS organisations



**5** learning events  
with overall learner satisfaction above 90%

**6** peer reviews  
by BOA

Monthly coaching conversations

Patient leaders working in collaboration with clinical teams to improve

The impact

**119** lives saved so far  
(compared with mortality rates at study sites before the collaborative)



**80%** of patients operated on within  
**36 HOURS** of admission

More than **100** EXTRA patients returned to their own home instead of a nursing or residential home

Reduced length of stay in hospital by 2 days

**10%** increase in patients mobilised on the day of or after surgery



Real time patient experience data reporting

**80%** of patients had a nerve block



**29,000** extra meals and weekly tea parties to boost nutrition

**5** nutritional assistants recruited and trained

RUBIS.Qi

The Health Foundation

Northumbria Healthcare NHS Foundation Trust

# Patient Experience Collaborative



Successfully launch hosted  
by Northumbria on 26<sup>th</sup>  
September 2017

12 organisations in the room

Testing Northumbria real  
time system at scale

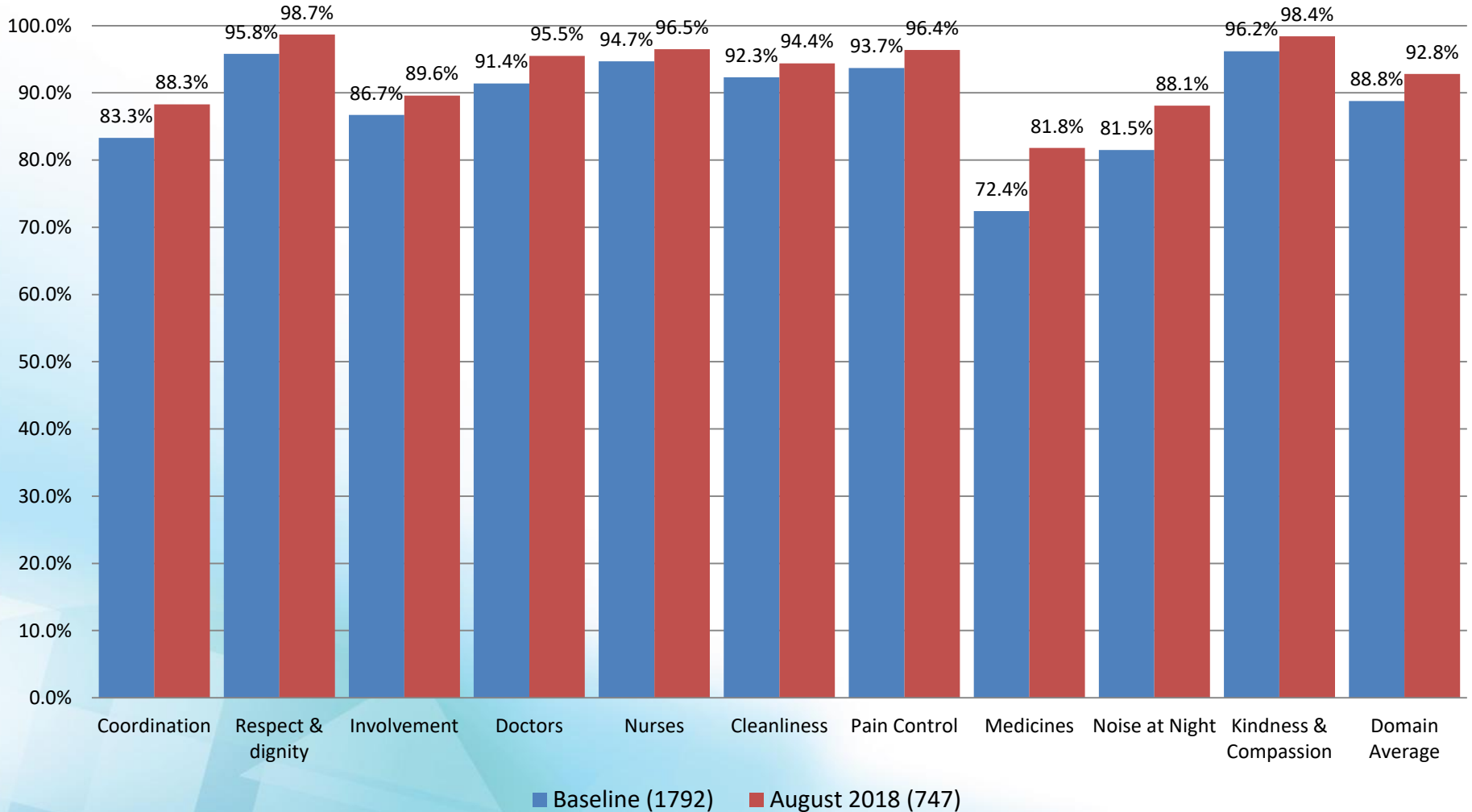
Opportunity to influence  
future policy

# Trust Significantly BETTER domains

|                      | Coordination | Respect & dignity | Involvement | Doctors | Nurses | Cleanliness | Pain Control | Medicines | Noise at Night | Kindness & Compassion | Domain Average |
|----------------------|--------------|-------------------|-------------|---------|--------|-------------|--------------|-----------|----------------|-----------------------|----------------|
| BHR                  |              |                   |             |         |        |             |              | Green     | Green          |                       |                |
| Belfast              | Green        | Green             | Green       | Green   | Green  | Green       | Green        | Green     | Green          |                       | Green          |
| Cwm Taf              | Green        |                   |             | Green   |        | Green       | Green        | Green     |                |                       |                |
| Ipswich & Colchester |              | Green             |             |         |        |             | Green        | Green     |                |                       | Green          |
| Taunton and Somerset |              |                   | Green       |         |        |             |              | Green     |                |                       |                |
| Torbay & South Devon |              | Green             |             |         |        |             | Green        |           |                |                       |                |

# PEN Collaborative Significantly BETTER in ALL domains

## PEN Collaborative Overall Domain Scores





# TWO SAMPLE t-TEST FOR COMPARING TRUST TO PICKER AVERAGE

|                       | PROBLEM SCORES           |                               | SAMPLE SIZE            |                         | t-value | SIG?   |
|-----------------------|--------------------------|-------------------------------|------------------------|-------------------------|---------|--|
|                       | Trust Problem Score (p1) | Picker Av. Problem Score (p2) | Trust Sample Size (n1) | Picker Sample Size (n2) |         |  |
| Coordination          | 83.3                     | 88.3                          | 1792                   | 747                     | -3.40   | Trust Significantly BETTER than Picker Average |
| Respect & dignity     | 95.8                     | 98.7                          | 1792                   | 747                     | -4.61   | Trust Significantly BETTER than Picker Average |
| Involvement           | 86.7                     | 89.6                          | 1792                   | 747                     | -2.11   | Trust Significantly BETTER than Picker Average |
| Doctors               | 91.4                     | 95.5                          | 1792                   | 747                     | -4.07   | Trust Significantly BETTER than Picker Average |
| Nurses                | 94.7                     | 96.5                          | 1792                   | 747                     | -2.10   | Trust Significantly BETTER than Picker Average |
| Cleanliness           | 92.3                     | 94.4                          | 1792                   | 747                     | -2.00   | Trust Significantly BETTER than Picker Average |
| Pain Control          | 93.7                     | 96.4                          | 1792                   | 747                     | -3.03   | Trust Significantly BETTER than Picker Average |
| Medicines             | 72.4                     | 81.8                          | 1792                   | 747                     | -5.33   | Trust Significantly BETTER than Picker Average |
| Noise at Night        | 81.5                     | 88.1                          | 1792                   | 747                     | -4.41   | Trust Significantly BETTER than Picker Average |
| Kindness & Compassion | 96.2                     | 98.4                          | 1792                   | 747                     | -3.42   | Trust Significantly BETTER than Picker Average |
| Domain Average        | 88.8                     | 92.8                          | 1792                   | 747                     | -3.32   | Trust Significantly BETTER than Picker Average |

**SIG?**

\*\*If t-value is greater than 1.96 or more negative than -1.96, the result IS significant. (95% confidence).  
 \*\*If the t-value is less than 1.96 or less negative than -1.96 the result is NOT significant. (95% confidence).

# # 5 Celebrate kindness and compassion



# Bringing safer care closer to home



**Kilimanjaro Christian Medical Centre - Tanzania**

Knitted  
with love



# What we've learnt

- The soft stuff isn't soft
- Frame the issues in ways that engage many - move them towards a shared purpose and new future
- Not a choice between stories or data but both
- Build internal systems that recognise values and behaviours
- Be realistic about change and prepare for the long haul
- Be flexible and keep refreshing the organisational story
- Protect the frontline – find the joy in improvement

# Public Participation team engagement resources and support 2019

March 2019



# Outline

- Why is it so important?
- Patient Experience vs Engagement (language)
- NHS England Public Participation Team and Support
- Tools and resources
- Learning and Development
- Best Practice Approach to Engagement – 10 steps

# Why is it important?

- Putting patients at the heart of what we do is central to NHS England's values.
- Working together with patients and the public is a core part of the NHS Constitution and our business objectives.
- Involving patients and the public is a requirement of NHS England under section 13Q of the Health and Social Care Act 2012, but more than that, evidence shows that working together brings about better commissioning and higher quality services.
- Meaningful engagement with people and communities is the transformational process the NHS needs in order to be effective in the long term and will support.....

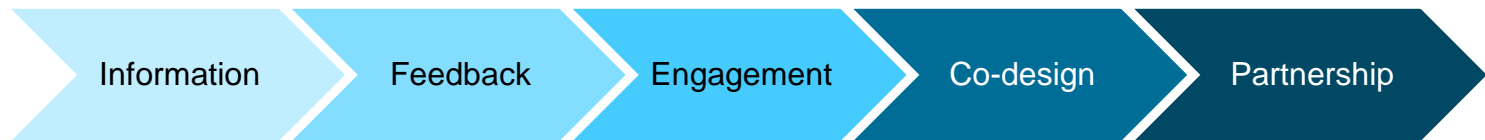


# Why is it important? – continued

- The power of ‘communities’ is harnessed
- Improved governance, quality of services, projects, programmes and outcomes
- Greater capacity building and learning
- Innovation and creativity
- Access to new resources, information and expertise
- Increased public awareness and understanding
- Increase staff moral
- Illness being prevented were possible as people are more engaged in their health and social care
- Any many other reasons

# Engagement and Experience part of the same continuum

It is sometimes helpful to think of patient experience and engagement activities existing on a continuum, where the amount of influence people can have over decisions varies.



# What is patient experience?

“**Patient experience** is what the process of receiving care feels like for your patients. **Understanding patient experience** can be achieved through a range of activities that capture direct feedback from patients, service users, carers and wider communities. These could include questionnaires or analysing complaints, through to Experience Based Design approaches.

Using experience to design better healthcare is unique in the way that it focuses so strongly on capturing and understanding patients’, carers’ and staff experiences of services, not just their views of the process.”

The Patient Experience Book – Institute for innovation and  
Improvement - 2013

# What is Patient and Public Engagement?

**“Patient and public engagement** is the active participation of patients, carers, community representatives, community groups and the public in how services are planned, delivered and evaluated. It is broader and deeper than traditional consultation. It involves the ongoing process of developing and sustaining constructive relationships, building strong, active partnerships and holding a meaningful dialogue with stakeholders.

It is also about engaging the public in decisions about the commissioning, planning, design and reconfiguration of health services, either pro-actively as design partners, or reactively, through consultation.”

The Patient Experience Book – Institute for innovation and Improvement - 2013

# What is public engagement

## What is public involvement in commissioning?

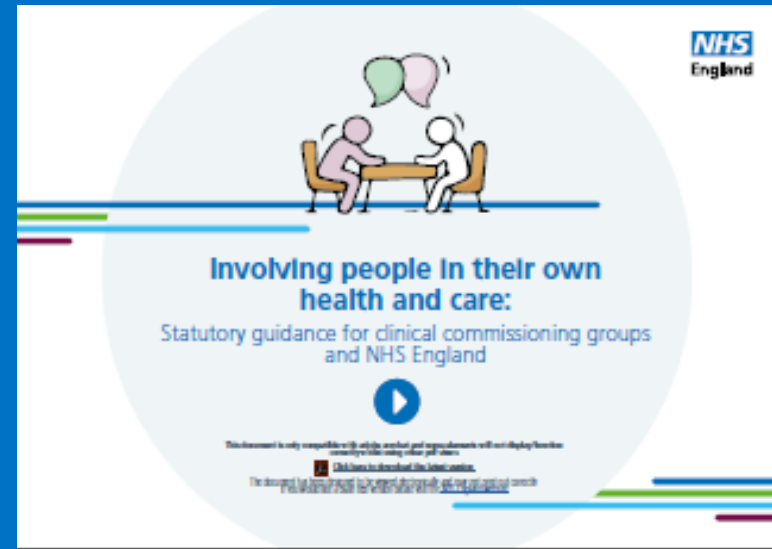
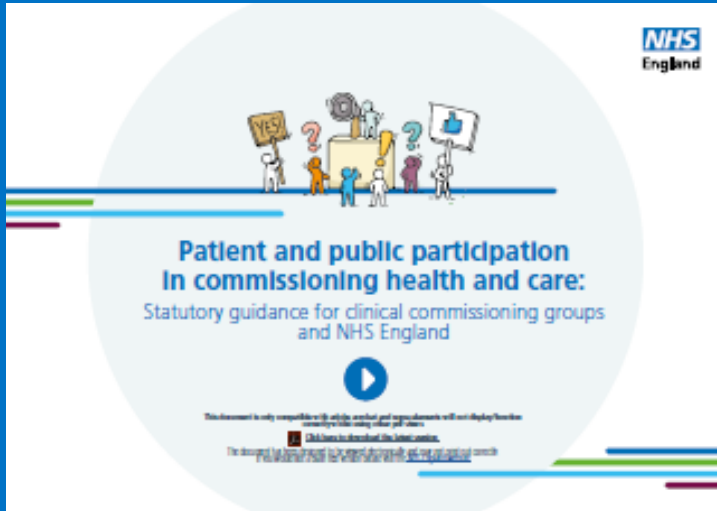
Public involvement in commissioning is about enabling people to voice their views, needs and wishes, and to contribute to plans, proposals and decisions about services. Our use of the term 'patients and the public' includes everyone who uses services or may do so in the future, including carers and families.

The term 'involvement' is used interchangeably with 'engagement', 'participation', 'consultation' and 'patient or public voice' and there are many different ways to involve patients and the public, as illustrated opposite. Different approaches will be appropriate, depending on the nature of the commissioning activity and the needs of different groups of people.



# Statutory Guidance: April 17

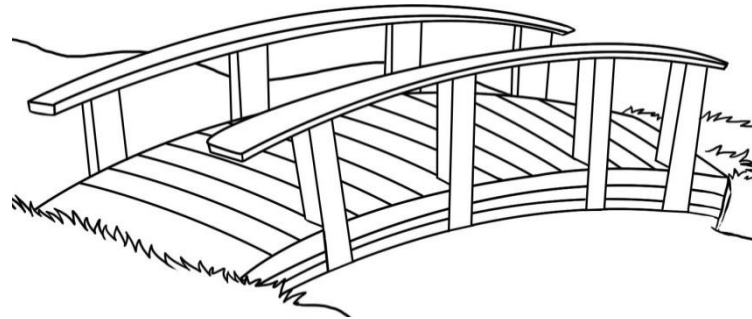
## Collective and individual legal duties



Use alongside NHS England commissioning frameworks and Patient and Public Participation Policy

# Public Participation Team

NHS  
England

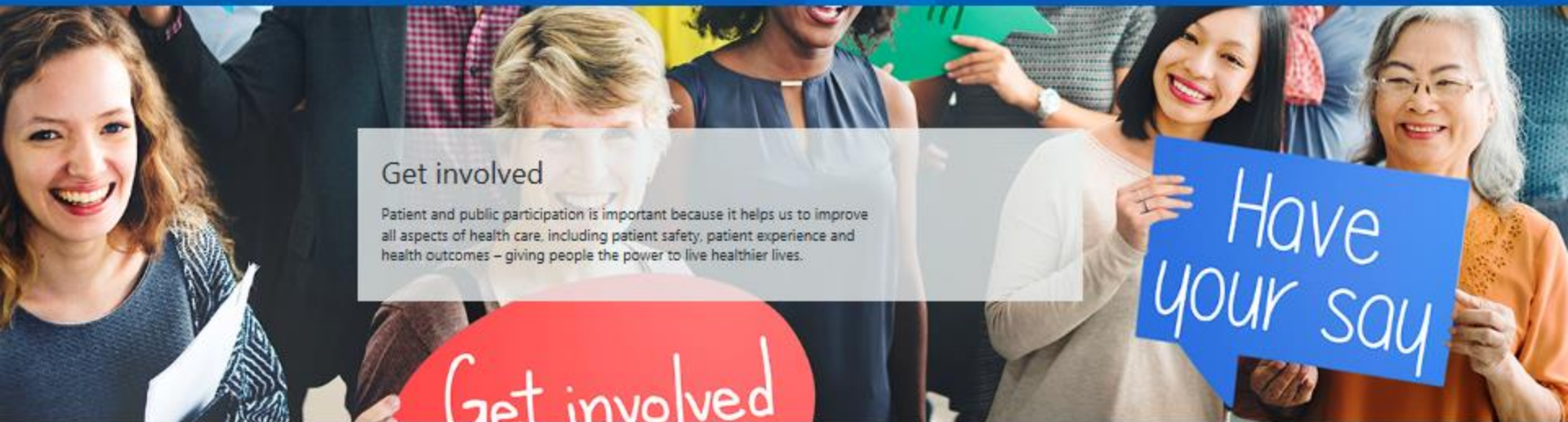


Members of  
the public  
their families,  
carers and  
supporters

# Advising and supporting colleagues







## Get involved

Patient and public participation is important because it helps us to improve all aspects of health care, including patient safety, patient experience and health outcomes – giving people the power to live healthier lives.

### About the Involvement Hub

A source of information for people who want to get involved in our work or enable others to participate.

### Learning and development

Workshops, webinars and elearning to improve understanding of the healthcare sector and participation.

### Guidance for commissioners

Statutory guidance for Clinical Commissioning Groups and NHS England on involving patients and the public.

### Good practice

Examples of good practice in involving people in healthcare services and service development.

### Surveys and consultations

Have your say on NHS England's current consultations and surveys.

### Resources

A variety of resources to support you in your involvement work, including bitesize guides to participation.

[How to get involved](#)



[Why get involved](#)



[Current opportunities](#)



You may also be interested in

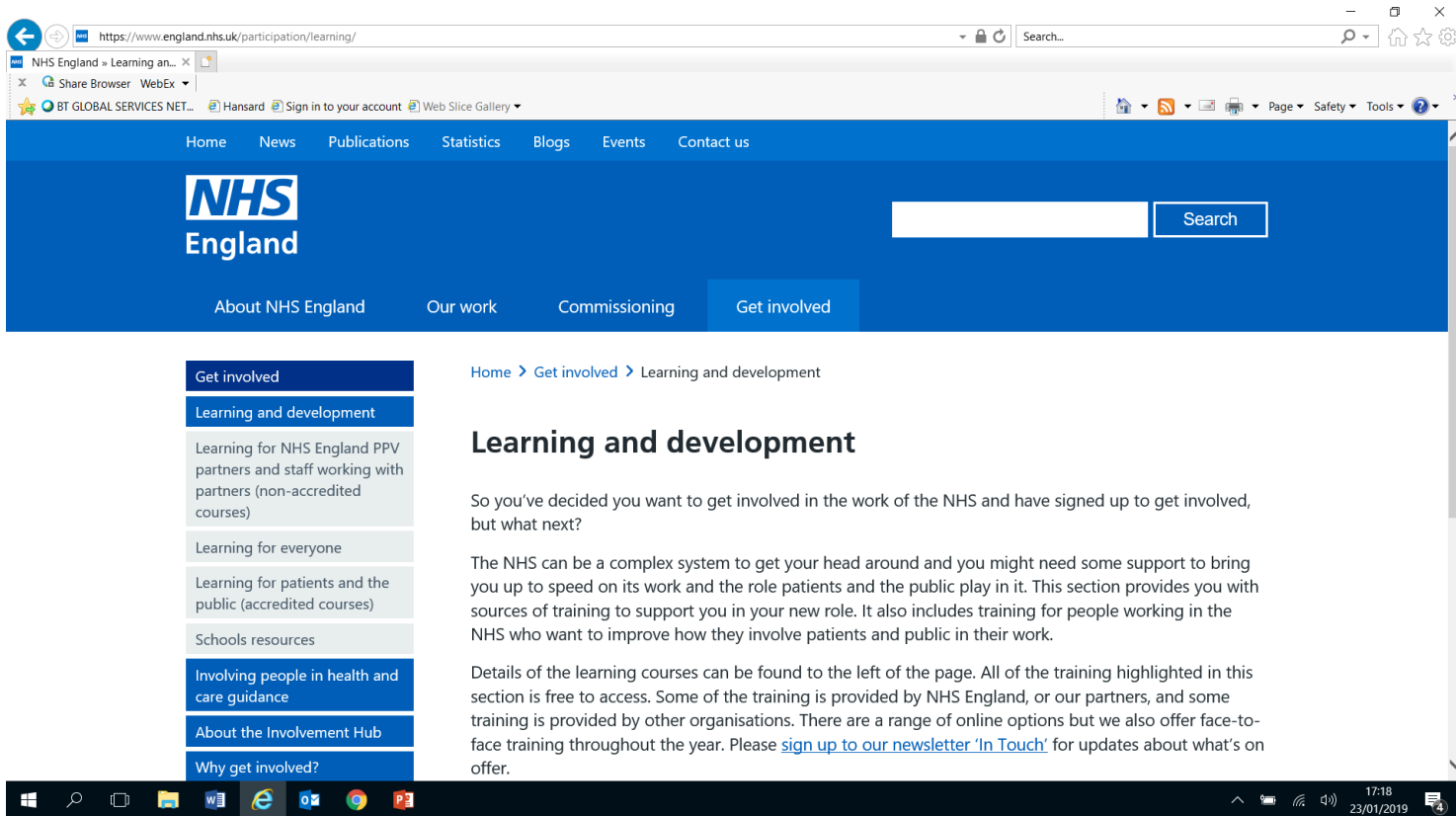
[An introduction to the NHS](#)

# Looking through the Involvement Hub

- **Guidance for commissioners** - Statutory guidance for Clinical Commissioning Groups and NHS England on involving patients and the public.
- **Surveys and consultations** - Have your say on NHS England's current consultations and surveys.
- **Good practice** - Examples of good practice in involving people in healthcare services and service development, community grants
- **Resources** – Bitesize guides, commissioning frameworks, expenses policy, patient and public voice policy, resources from other organisations
- **Current opportunities** – A space to add current NHS England Patient and Public Voice roles that people can apply for

(We will cover learning and development separately)

# Learning & Development



The screenshot shows a web browser displaying the NHS England Learning and Development page. The browser address bar shows the URL <https://www.england.nhs.uk/participation/learning/>. The page features a blue header with the NHS England logo and a search bar. Below the header is a navigation menu with links for Home, News, Publications, Statistics, Blogs, Events, and Contact us. The main content area is titled "Learning and development" and includes a breadcrumb trail: Home > Get involved > Learning and development. The page text explains that the NHS is a complex system and provides training to support staff, patients, and the public. It mentions that training is free to access and includes both online and face-to-face options. A sidebar on the left lists various learning and development topics, with "Learning and development" highlighted. The Windows taskbar at the bottom shows the time as 17:18 on 23/01/2019.

Home > Get involved > Learning and development

## Learning and development

So you've decided you want to get involved in the work of the NHS and have signed up to get involved, but what next?

The NHS can be a complex system to get your head around and you might need some support to bring you up to speed on its work and the role patients and the public play in it. This section provides you with sources of training to support you in your new role. It also includes training for people working in the NHS who want to improve how they involve patients and public in their work.

Details of the learning courses can be found to the left of the page. All of the training highlighted in this section is free to access. Some of the training is provided by NHS England, or our partners, and some training is provided by other organisations. There are a range of online options but we also offer face-to-face training throughout the year. Please [sign up to our newsletter 'In Touch'](#) for updates about what's on offer.

- Get involved
- Learning and development**
- Learning for NHS England PPV partners and staff working with partners (non-accredited courses)
- Learning for everyone
- Learning for patients and the public (accredited courses)
- Schools resources
- Involving people in health and care guidance
- About the Involvement Hub
- Why get involved?

# Learning and Development Support

- eLearning modules
- Online accredited courses
- PPV Partner training around impact and influence
- Coaching and mentoring programme for PPV partners
- Staff and partner training on 10 Steps to even better public engagement

# Courses and training partners

## Online - [links](#)

- PPV Partners induction webinars
- 11 e-learning courses incl. carers, health inequalities, Commissioning Cycle
- Popular ones are using social media to engage effectively with patients and public and developing excellent relationships with PPV Partners
- Three can be used for PPV mandatory training – safeguarding, equalities and diversity, Information Governance

## Face to face courses

- Patient and Public Voice (PPV) partners training on influence and impact

# Courses and training - continued

## Staff training

- Access to all PPV training and e-learning
- 10 steps to even better public engagement

# Patient and Public Voice (PPV) partners training on influence and impact

**What is it?** Two days of interactive and fun classroom-based learning with a focus on influencing change, and developing skills and confidence to make the most of the Patient and Public Voice (PPV) partner role.

**Who is it for?** For PPV partners involved in NHS England or supporting transformation programmes (STP, ICS, etc.) on a regular basis. It is aimed at those working to support major change but who are less experienced in their role. There are also limited places for staff who support PPV roles.

**What does it cover?** Understand how you (a PPV partner) fit in to the wider health and social care landscape and how you can position yourself for greater impact. Gain a clear and shared understanding of the role and key responsibilities of a PPV representative. Explore effective skills for influence and collaboration through partnership working. Increase your confidence and identify some clear actions to take away.

Travel expenses and overnight accommodation will be provided based on individual need.

**100% of previous participants say they would recommend this course to others.** To find out more, please email [england.ppve-learning@nhs.net](mailto:england.ppve-learning@nhs.net)

# 10 steps to even better public engagement

Want to know more about patient and public engagement, understand the key legal responsibilities in this area and learn more about a 10 Step approach based on best practice?

This one day course is aimed at colleagues from NHS England and CCGs who are engaging with patients and the public, or who want to involve them more in our work programmes, in particular commissioning staff, policy development staff, business or project teams who are working with patients. We also welcome partner organisations and patient experts.

## **The full day session includes:**

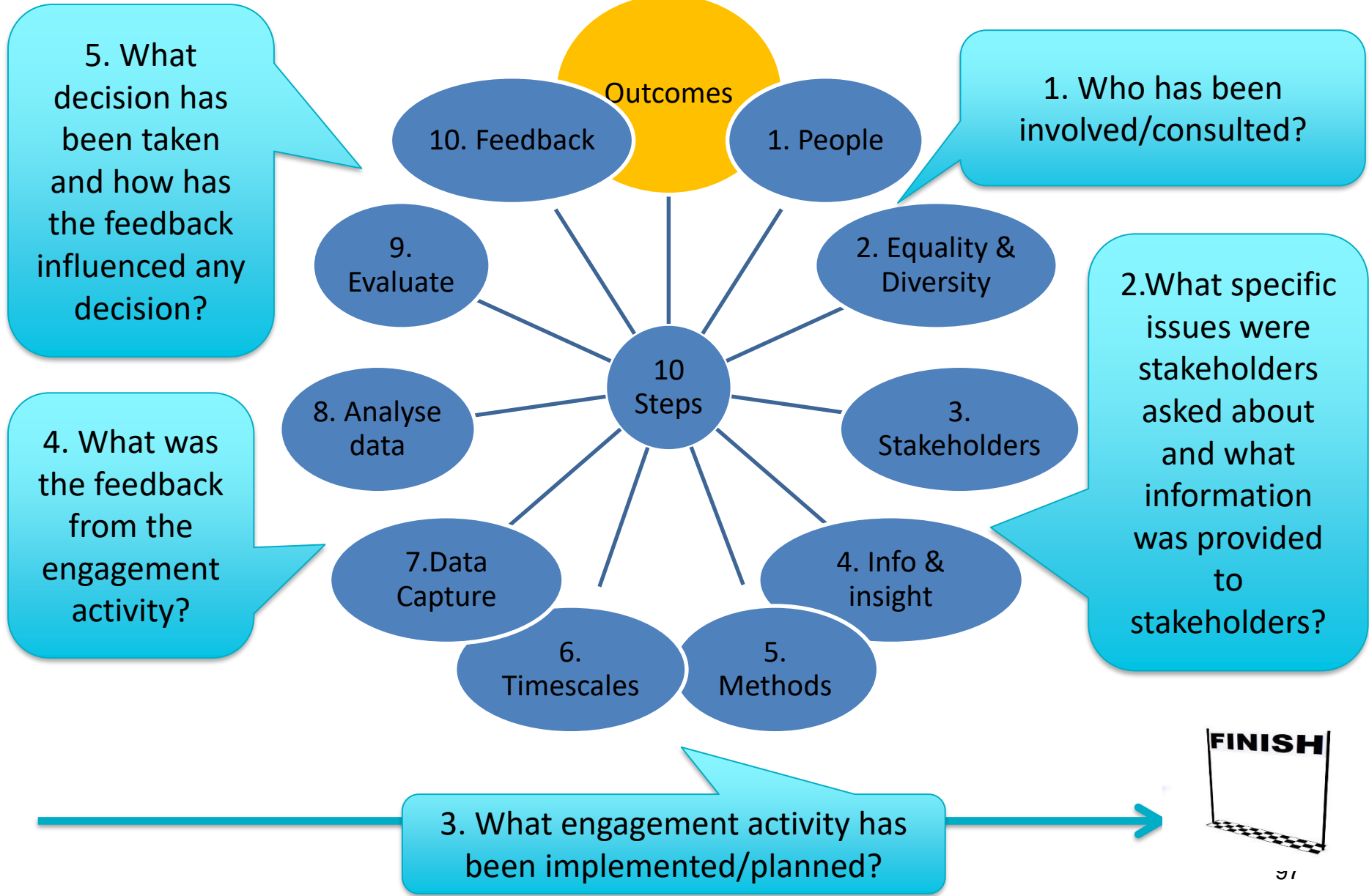
The core principles and benefits of involvement, the key legal duties in relation to engagement and health inequalities, good practice, practical tips and activities. Working in small groups to draft an engagement plan for an engagement topic(s) chosen by participants

**100% of delegates report they have learnt something new**

For more details, contact: [england.ppve-learning@nhs.net](mailto:england.ppve-learning@nhs.net)



# 10 Steps



# Personal impact - Chris Walker

- Connections with NHS England
- Supported the development of offers including the coaching and mentoring programme
- Accessed resources and support personally
- My volunteering journey
- Accessed development for others – including ‘10 steps’

# Tools and resources - sign up



1. Sign up to the [Future NHS website](#), email [Jonathan.leahy@nhs.net](mailto:Jonathan.leahy@nhs.net) The Future NHS website is shared workspace for system transformation engagement and communications colleagues, and brings together colleagues from local, regional and national teams to share information, ideas and resources without the need for central direction or 'sign off'.
2. [NHS Future Health and Care update](#) (Newsletter) [sign up](#) The Future Health and Care update provides the latest news and events every two weeks on integrating health and care across the country, including examples of best practice from NHS, local government and voluntary sector partnerships.
3. [NHS England People Bank](#) sign up for Patient and Public Voice partners – Please email: [Nhsengland.peoplebank@nhs.net](mailto:Nhsengland.peoplebank@nhs.net) The NHS People Bank is a Customer Relations Management (CRM) system which has been designed to directly connect citizens to information about involvement opportunities and to support citizens to get involved in participation activities.
4. [In Touch Newsletter](#) [sign up](#) In touch provides a fortnightly public overview of the latest NHS England news, events and consultations. Subscribe receive offers of recruitment onto advisory groups, and are the first to hear about public participation opportunities to help them people involved in our work.

# General – useful connections

- Public Participation Team rota - [england.engagement@nhs.net](mailto:england.engagement@nhs.net)
- [NHS Citizen twitter account](#)
- [NHS Citizen Facebook page](#)
- [Involvement Hub](#)

# Connections and networks

- [NHS Youth Forum](#)
- Older persons sounding board
- [NHS England Learning Disability and Autism Forum](#)
- Learning Disability and Autism Network
- Transgender Network
- [NHS Citizen](#)
- [Healthwatch England](#)
- VCSE [Health & Wellbeing Alliance](#)
- Patient Participation Groups and the [National Association for Patient Participation](#)
- CCG Lay member network



**South Tyneside and Sunderland  
Healthcare Group**

# Macmillan Cancer Improvement Manager

Kelly Craggs

# Patients at the Centre

- Roles and Responsibilities
- Why is patient involvement important
  - Feeling involved
  - Feel they are listened to
  - Empowered
  - Can feel more positive
  - Active participants in their care
  - Partnership with professionals and the service
  - Encourages open and honest communication
  - Better understanding of patients needs
  - Understanding what matters most to patients.

# Involvement within clinical practice

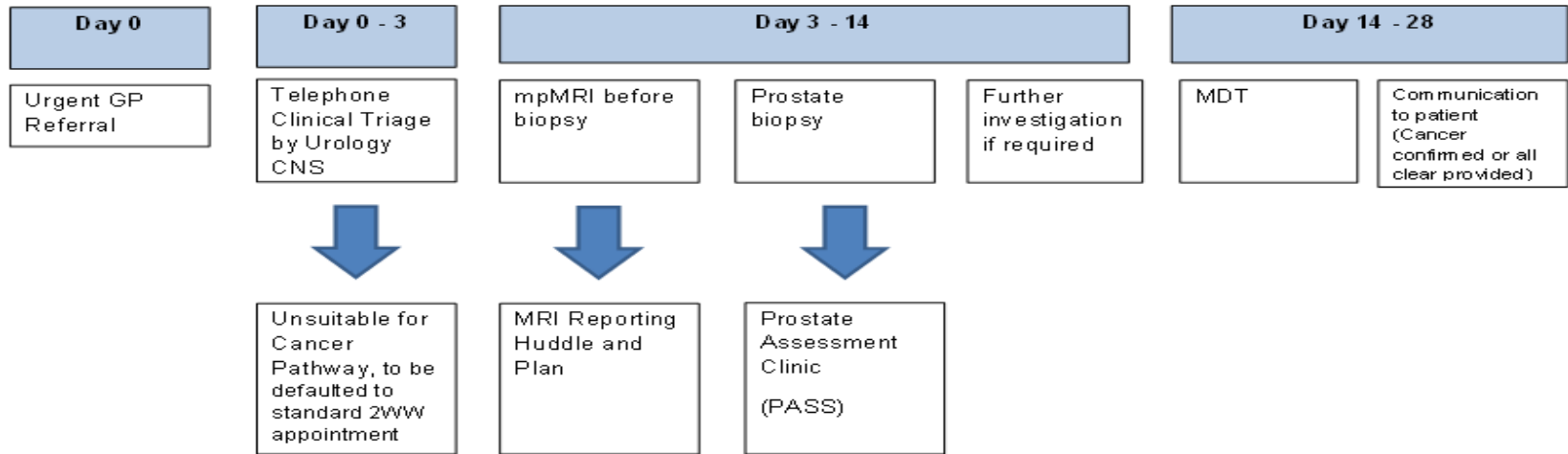
| Challenges                         | Benefits                              |
|------------------------------------|---------------------------------------|
| Time                               | A force for change                    |
| Resource                           | Advanced communication skills         |
| Skill                              | Advocacy skills                       |
| Culture around patient involvement | Can change attitudes, values, beliefs |
| Unrealistic expectations           | Creates opportunity                   |



# Patient involvement in pathways

## Prostate and Vague Symptoms

### Prostate



### Methods

- Mapping patient touch points
- Developing Questionnaires
- Creating opportunity for co-design

### Next steps

- Analysis
- Co- design group
- Further developing the pathway

The path to **excellence**

# Patient Representation in a Project Steering Group

## Highlights



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- Involved in the planning and development of the LWBC project
- Involved in all of the communications Internal and External
- Guest speaker in delivery at TITO
- Involved in Health and Well being events.

The path to **excellence**

# Key Messages

- Constant measure of patient satisfaction
- Involvement does not need to be structured
- Part of day to day professional and patient interaction
- Changing the culture
- Must be part of all transformation work

The background of the slide is a light gray gradient with several realistic water droplets of various sizes scattered across it. The droplets have highlights and shadows, giving them a three-dimensional appearance. The main title is centered in the upper half of the slide.

# MY PATIENT INVOLVEMENT JOURNEY

CLARE DONEY

SERVICE IMPROVEMENT LEAD FACILITATOR

# MY PERSONAL STORY

- ◎ 20 YEARS OF NURSING IN THE NORTHERN CENTRE FOR CANCER CARE
- ◎ SPECIAL INTEREST IN SERVICE IMPROVEMENT UNDERPINNED BY SERVICE USER FEEDBACK
- ◎ STUDIED THE THEORY BEHIND CO-DESIGN DURING MSC IN HEALTHCARE LEADERSHIP
- ◎ CURRENT ROLE WITH THE NORTHERN CANCER ALLIANCE

# MY STARTING POINT – THE IDEAL!

- CO-DESIGN
- REPRESENTATION ON ALL WORKING GROUPS
- BESPOKE FORMAL FEEDBACK
- QUANTIFIABLE DATA
- CAPTURING ALL VOICES



# CHALLENGES

- OVERCOMING EXPECTATION
- UNDERSTANDING THE SPECTRUM OF INVOLVEMENT
- COMPROMISE
- TIME FRAME
- CHANGING THE LANGUAGE WE USE
- CAPTURING INVOLVEMENT WITHOUT BIAS
- CLINICIAN ENGAGEMENT – OPEN TO WHAT MAY BE SAID




It's part of the new patient feedback protocol.



# MY ACHIEVEMENTS – REALISTIC INVOLVEMENT...

- COLLABORATION AND SHARING
- SOURCES OF INVOLVEMENT
- RECORDING OF INFORMATION RECEIVED
- THE POWER OF A PATIENT STORY
- CLINICIAN ENGAGEMENT

# THE BENEFIT OF HINDSIGHT

- 
- Use every opportunity to seek patient involvement
  - All feedback is valuable, no matter how small
  - Spread the word that it doesn't need to be hard
  - We may not get it right for everyone
  - Try hard to listen to your own bias
  - Find out about what we already know
  - Share our patients voices (with consent)

*There is a difference between*

**TRULY  
LISTENING**

*& waiting for your turn to talk.*

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**



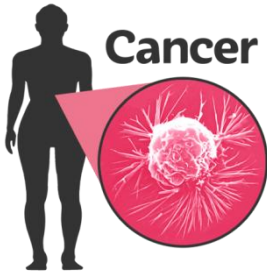
# **‘Be cancer aware’**

**Time to all talk about cancer**

**A co-production project**

**Julie Tucker, Sharon Bell, Gavin Barr and  
Jodie Williams**

# Be cancer aware



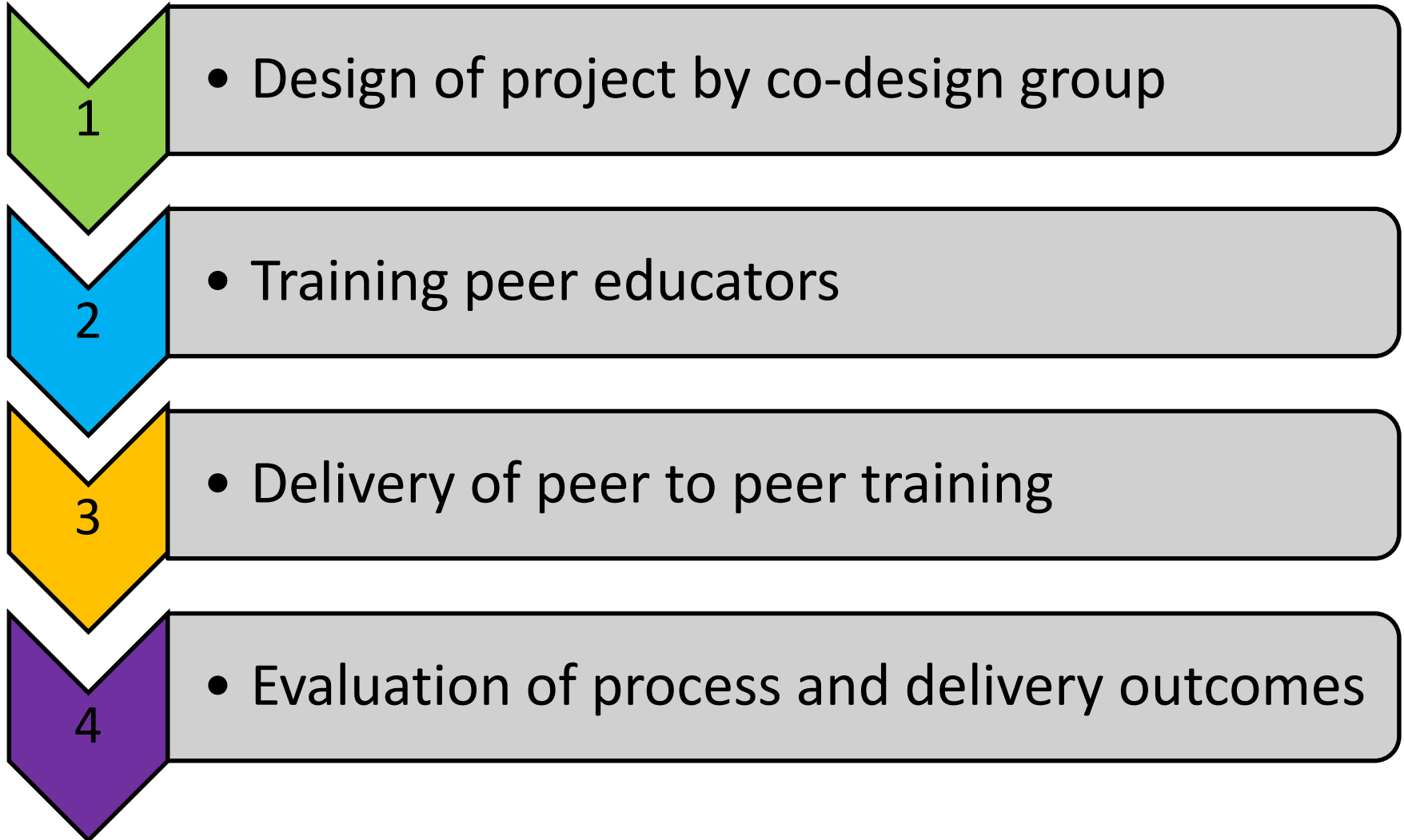
A cancer awareness course

Designed, developed, delivered and evaluated in partnership

A resource delivered to building knowledge and skills



# Development stages



# Design



We had 2 days to design the course



We started with a blank piece of paper

We all gave our ideas and shared ideas we had collected from colleagues

The work and ideas were transformed into our course



# Design



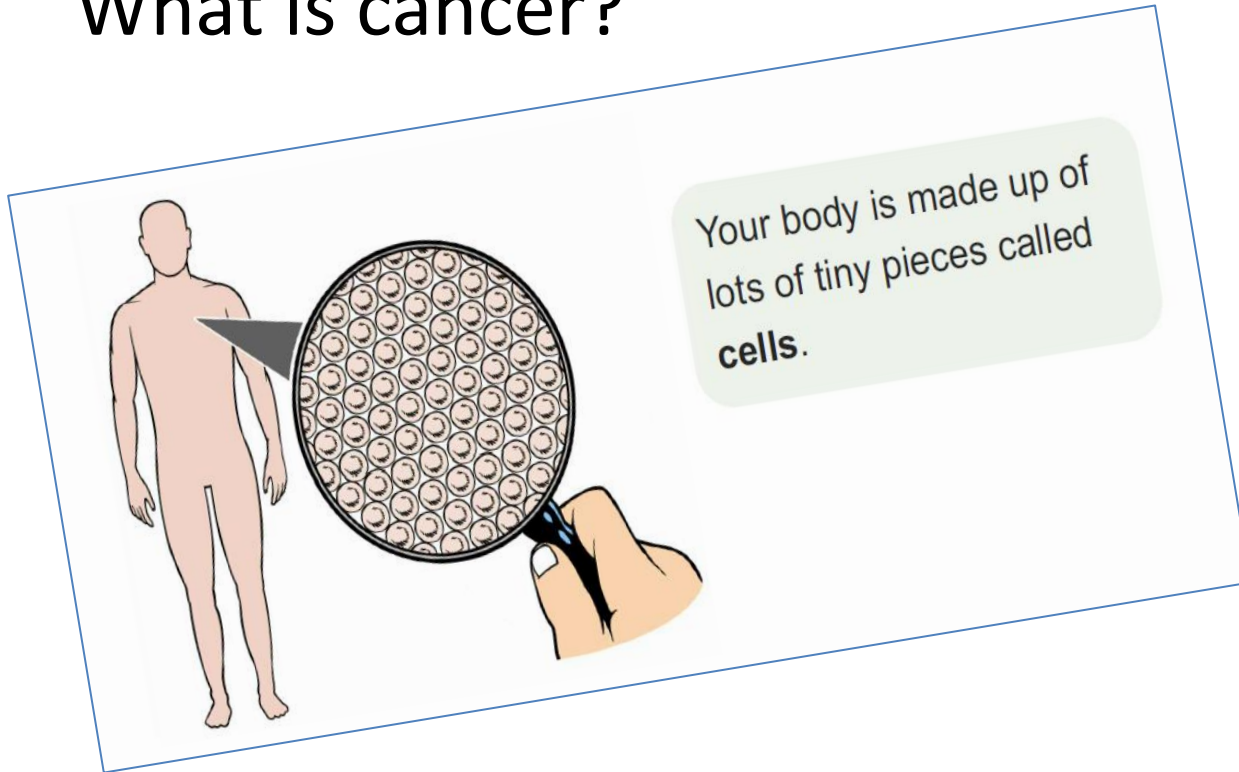


# The course

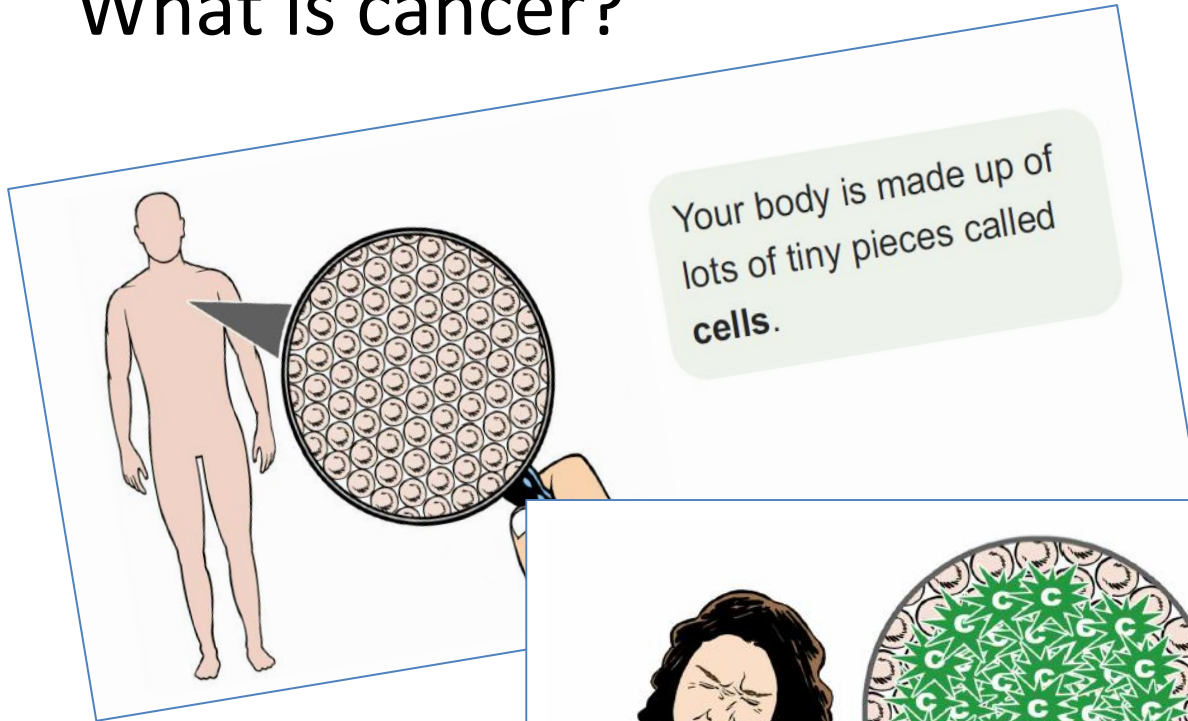
- What people feel about cancer
- What is cancer?
- Myths about cancer
- Understanding cancer
- Signs of cancer
- Cancer pathway
- Cancer prevention
- Cancer screening
- Cancer support

# The course

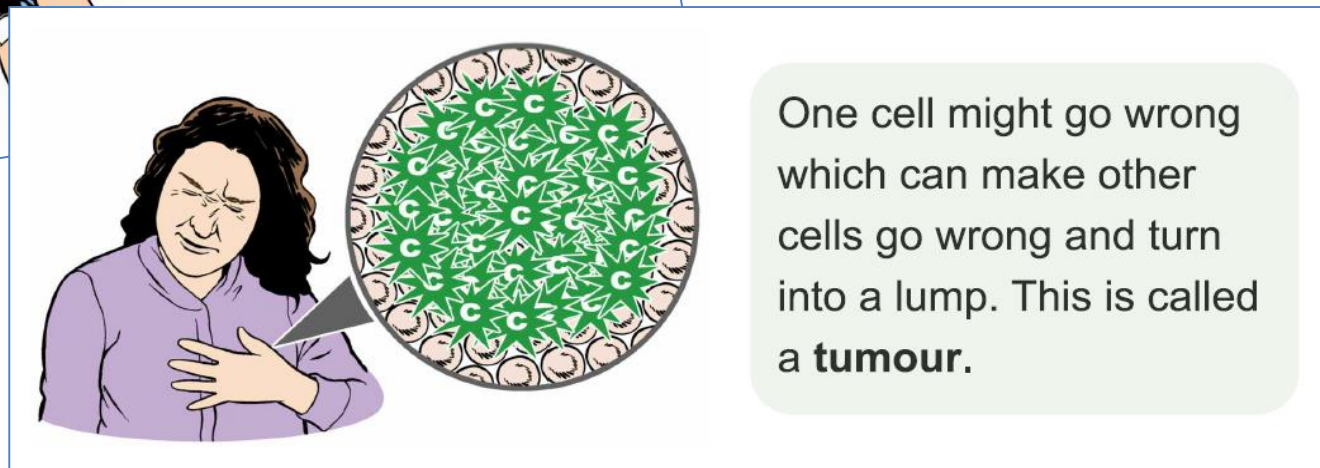
## What is cancer?



## What is cancer?



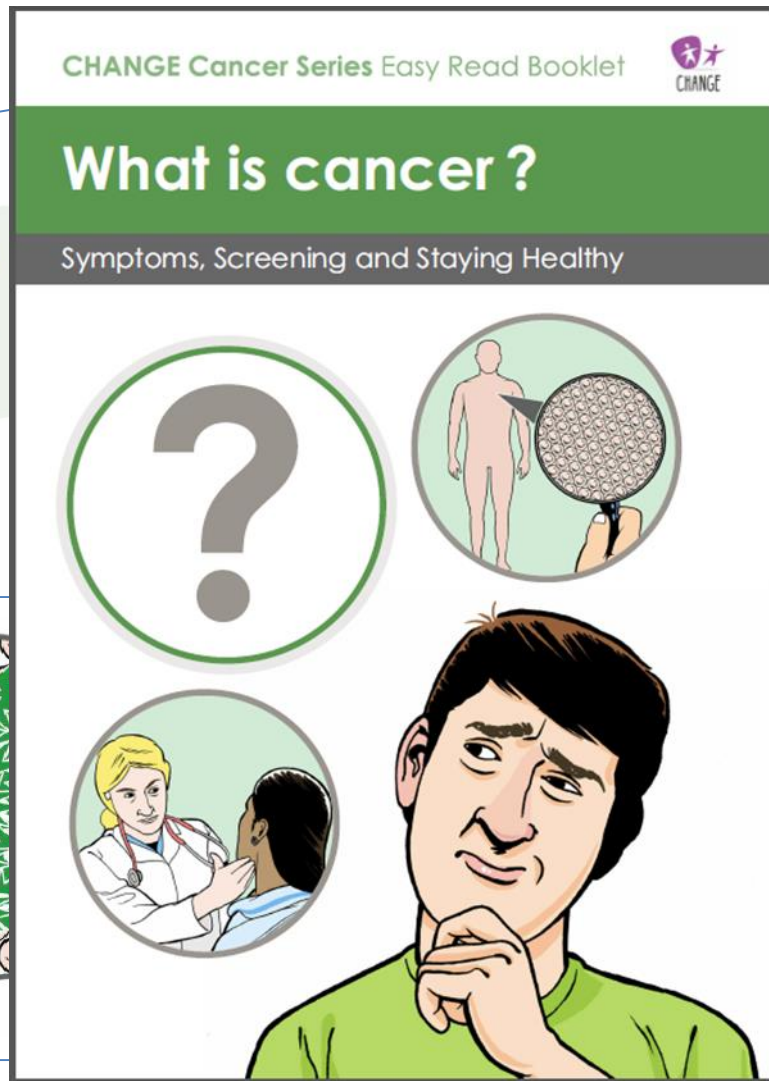
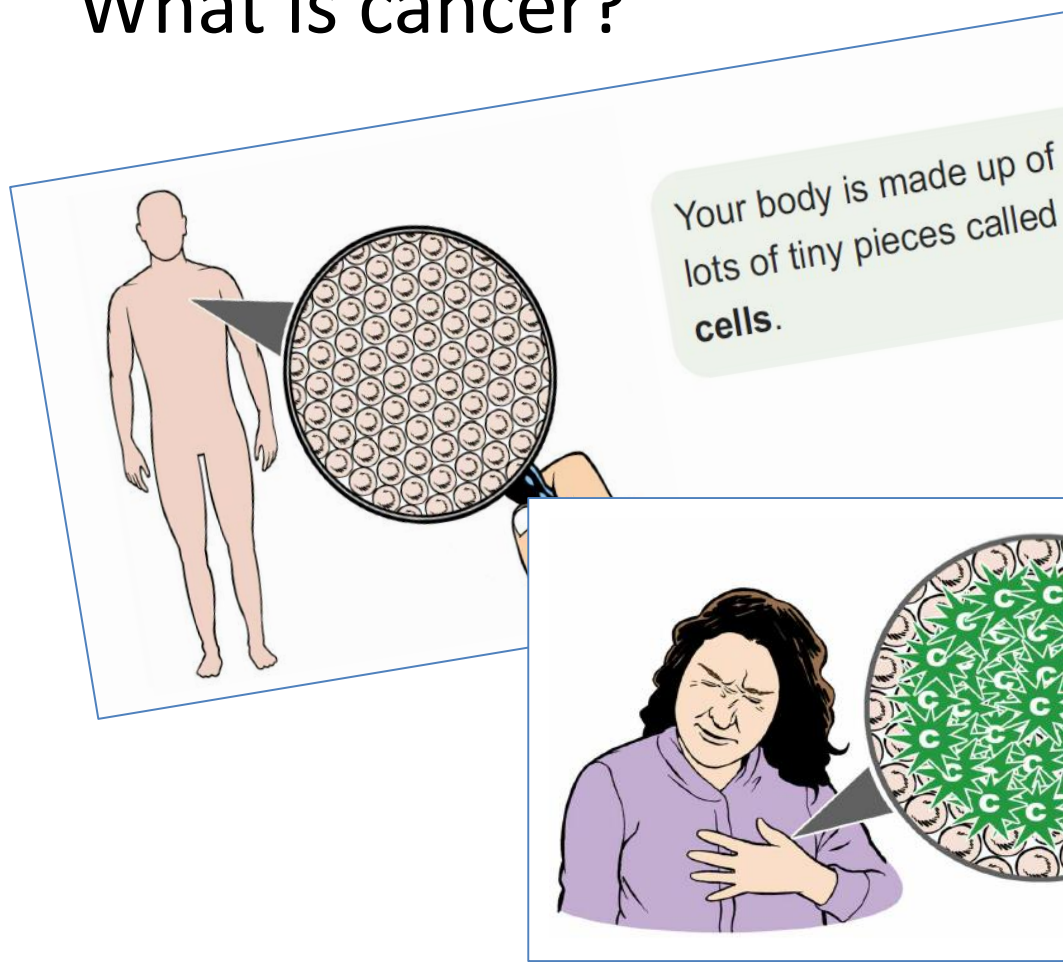
Your body is made up of lots of tiny pieces called **cells**.



One cell might go wrong which can make other cells go wrong and turn into a lump. This is called a **tumour**.

# The course

## What is cancer?



## Myths about cancer

Yes



No



Sometimes



## Myths about cancer

If you have a cancer you will be able to feel a lump

Choice yes, no or sometimes



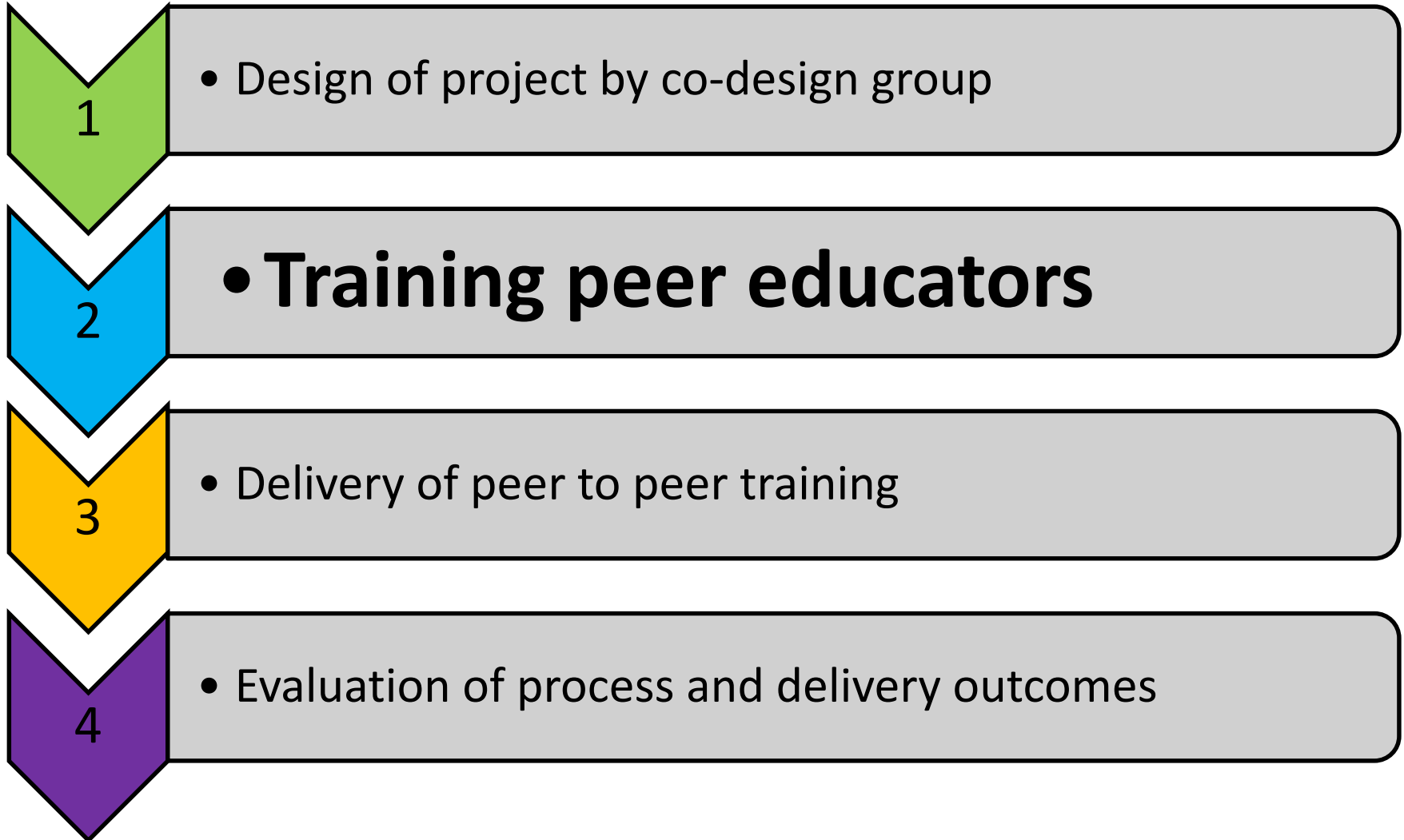
# The course

## Sharon's story

[https://youtu.be/\\_zH-x0YVrzw](https://youtu.be/_zH-x0YVrzw)



# Development stages





# Training

We invited people to train as peer educators

5 groups completed the training



# Training

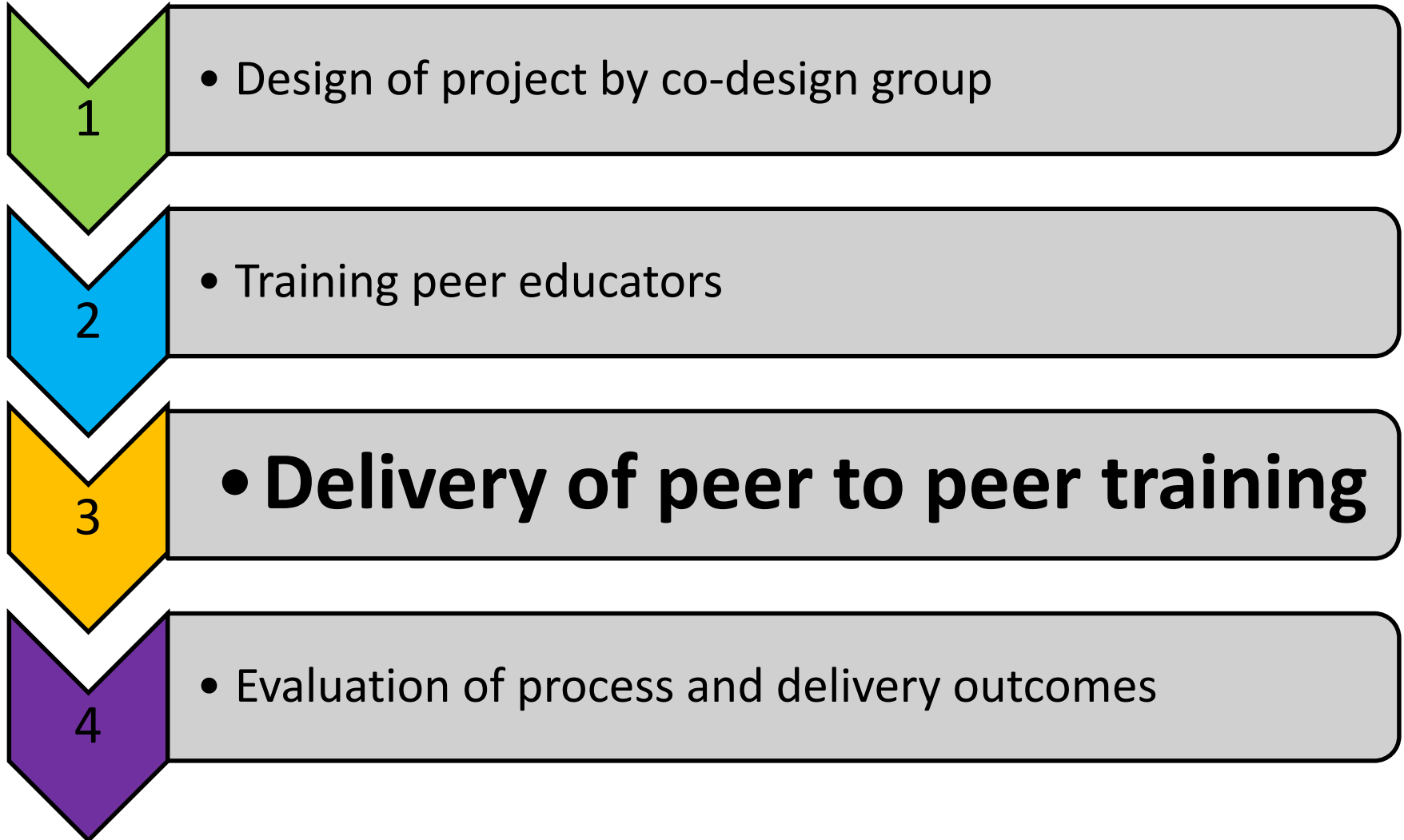


Our training day was in November

- We learnt about the course
- We made new friends
- We got our course packs
- We practiced delivering the course



# Development stages



# Delivery

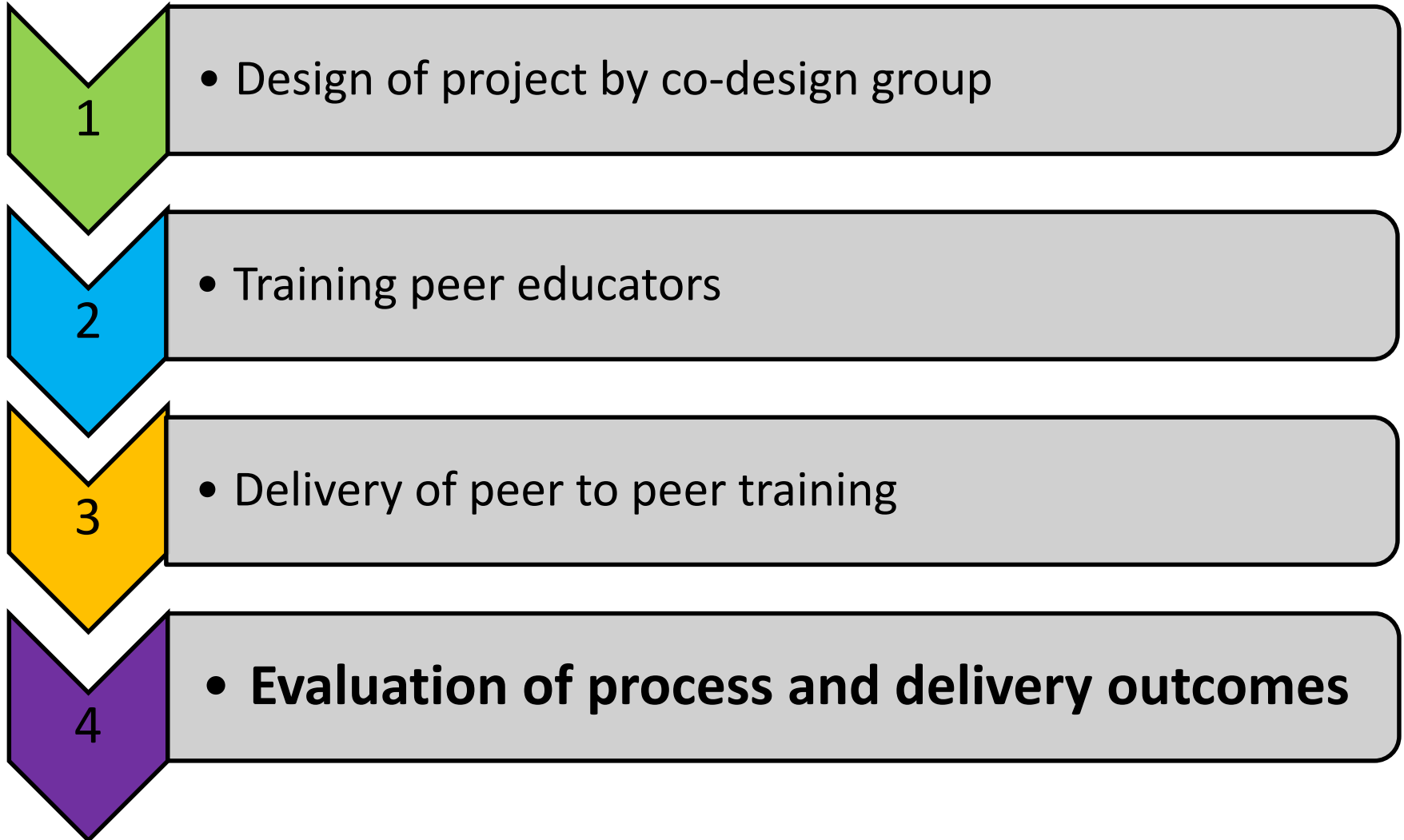
5 organisations will each deliver 10 'Be cancer aware' courses

Each organisation is at a different stage;

Planning training and organising groups to visit

Delivering training (5 courses so far)

# Development stages



# Evaluation



## Evaluation of the process

- Benefits of co-production
- Challenges
- Delivery

## Evaluation of the outcomes

- Number of people trained
- Increase in knowledge



# Evaluation of process



“It was exciting to design the course, I learnt so much being involved”

“Proud it’s my course, I helped to make it”

“All our knowledge and experiences shaped the course”

“we are all equal and all had our say”

# North Tyneside Cancer Plan

**Tom Dunkerton**

**Commissioning Manager - North Tyneside CCG**

**Liam Ryan**

**Engagement Lead Macmillan**

**Jo Mackintosh**

**Macmillan Engagement & Co Design project Manager**





# Principles

- Accelerate progress across the health and care system
- Work with all partners across the ICS to ensure there is a sufficient and skilled workforce to meet demand
- Continue to reduce variation by improving quality of referrals and improve access to screening
- Develop a care coordinated approach as if it were an LTC
- Ensure patient experience for cancer care is high across both primary and secondary care



# National Cancer Patient Experience Survey Results 2017

- 83% of respondents said they were definitely involved as much as they wanted to be in decisions about their care and treatment
- 94% said they were given the name of a clinical nurse specialist who would support them through their treatment
- 87% of respondents said that it had been 'quite easy' or 'very easy' to contact their clinical nurse specialist
- 91% said overall, they were always treated with dignity and respect while they were in hospital
- 97% said hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital
- 59% said they thought GPs and nurses at their general practice definitely did everything they could to support them while having cancer treatment



# Local Approach

- As CCG we needed to understand the local picture on how cancer pathways worked, what the challenges are, what works well and where improvements are needed
- To do this we needed to bring a range of stakeholders together including both frontline staff, public health and the voluntary sector to get all their perspectives and an indication of how the system works
- From that we established the Steering Group who then began the work to identify key priorities and agree key actions



# Establish patient experience on par with clinical effectiveness and patient safety

- Ensure that patient experience for cancer is high across primary and secondary care
- To develop an engagement and experience strategy
- To ensure all ideas received when discussing how to engage service users are considered when developing the engagement strategy



# North Tyneside Cancer Plan Priorities

Spearhead a radical upgrade in prevention and public health

Achieve earlier diagnosis

Establish patient experience on par with clinical effectiveness and patient safety

Transform our approach to support people living with and beyond cancer

Make the necessary investments required to deliver a modern, high quality service

Ensure commissioning provision and accountability processes are fit for purpose



# The story so far – Phase 1

- Three organisations working in partnership to look at how we involve patients
- Initial meeting in October 2018 to engage patients/carers and the public – low turnout
- Continuous learning & improvement – we quickly realised we needed to change our approach
- Creation of task & finish group to design future engagement



# The story so far – Phase 2

- T&F group includes patients/carers/public/third sector – reach into community and fresh perspectives
- Has played full role in developing ideas – original partners in more supporting role
- Has developed new event on 21<sup>st</sup> March with much greater uptake
- Has also reached into numerous other events and engaged harder to reach groups



## Next steps.....

- Understand what matters most to people by gathering views and experiences at the event on the 21<sup>st</sup>.
- Recruit people to work in partnership with the cancer locality group to develop and implement the locality cancer plan going forward
- Co design an integrated approach to involving people in the locality cancer plan
- Continue to develop links with community organisations that facilitate and support effective involvement.





# What have we learnt so far?

- The ideas and challenge that the T&F group members bring have helped us to think and work differently.
- The experience of partnership working shapes and influences our thinking beyond the work of the project.
- We grow as individuals when we work together:

*“I now fully appreciate the benefits of collaborative working across organisations and have found this experience not only very enjoyable but invaluable in moving Priority 3 of the North Tyneside Cancer Plan forward. I have also found working with members of the public very rewarding and believe that without their input our March event would not have generated as much interest as it has”*



# Northern Cancer Alliance

## Coproduction in cancer service development in County Durham

Kirsty Wilkinson,  
Public Health Advanced Practitioner  
Durham County Council

# What is Coproduction?



<http://coalitionforcollaborativecare.org.uk/a-co-production-model/>

# Why Coproduction?

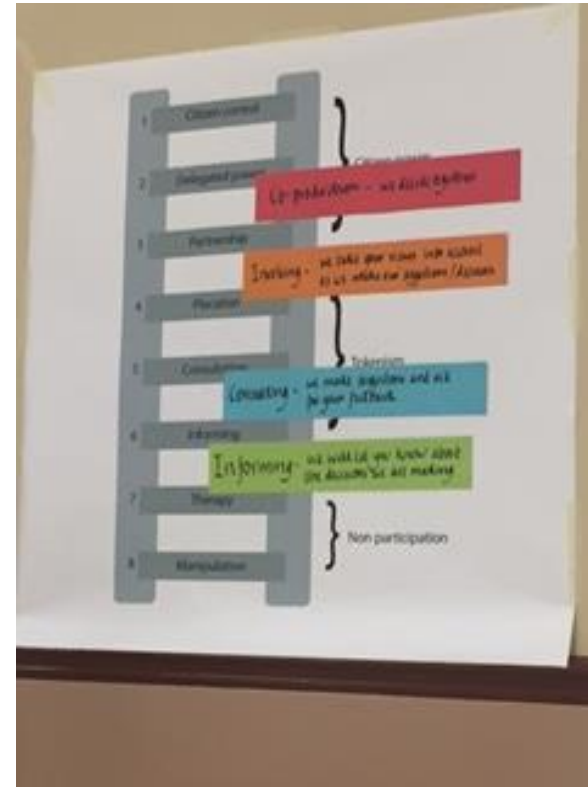
- When developing organisational change, it's important to know that you're working towards what really matters to the people you support and your wider stakeholders.
- Empowering people who use services, their carers and families to play a leading role in shaping and driving the changes **they** want to see.

# Coproduction

- Workshop
- Framework
- One Page Profile
- Coproduction volunteer recruitment
- Coproduction Group
- Consultation
- Recognition

# Workshop

- What is coproduction?
- Good practice in Coproduction
- Working together for change
- Coproduction Groups
- One Page Profiles



# Coproduction Framework

## Vision:

- People affected by cancer will work together with the local authority and other key partners in the shaping and design of Macmillan Joining the Dots solutions which aim to improve the wellbeing and quality of life of people affected by cancer who live, work and study in County Durham through focusing on support around personal issues such as practical, financial, emotional, relationship, spiritual and lifestyle.

# Coproduction Framework

## Principle 1:

- People affected by cancer (those who have or have had a cancer diagnosis, their families or carers) will be involved throughout the Joining the Dots process from idea to delivery, and quality assurance.

## Principle 2:

- People affected by cancer have the confidence to share their knowledge and experiences; and their knowledge and experiences are displayed in their own words and harnessed in key decisions about Macmillan Joining the Dots.



# Coproduction Framework

## Principle 3:

- It is clear how decisions are made and people affected by cancer are, and feel as though they are, involved in the decision making about Macmillan Joining the Dots.

## Principle 4:

- Meetings, materials and venues are accessible for people affected by cancer – people can get there, have their out of pocket expenses reimbursed, be heard and have access to reports and notes of meetings.

# One Page Profiles

- Personalisation
- Knowing what really matters
- Better relationships
- Better support
  
- What people appreciate/like about me?
- What is important to me?
- How best to support me

## My One Page Profile

Hello my name is Kirsty Gail Wilkinson (call me Kirsty)



### What people like about me?

- Friendly
- Approachable
- Can do attitude
- Passionate about my job
- Honest
- Humorous
- Fair

### What is important to me...

- My family: children; Zach (Age 11) and Neave (Age 7), my husband; Steven, my mum; Ann, my sister; Nicola, my nephews; Lewis, Ryan, Jordan and Ben; my grandparents; Olive and Harold (both of whom are 93) and numerous aunts, uncles and some of my cousins who I won't name here! I see my mum (Ann) every day before and after work - she is my lifeline and a tremendous support.
- My friends, particularly the girls I went to school with (Beverley, Suzanne, Jill, Lesanne, Alison, Claire and Rebecca) and those who I lived with at University (Natalie, Wendy, Rachel, Laura, Heather and Louise). I don't see them as often as I would like but we have lots of fun when we get together.
- Being able to spend quality time (having fun, reading together or watching films) with my children, and being able to pick them up from or drop them off at school at least once a week and watching them in their out of school activities (Football for Zach and gymnastics for Neave).
- Member of the cast and crew at [Kymren](https://www.kymren.com/) (https://www.kymren.com/) an epic tale of England an open air show. I'm a dancer in Team 10. If you haven't heard about it see the link above and click on book tickets! Last year we were presented with the Queen's Award for Volunteering!
- Sharing the burden of cooking tea each night with my mum, I cook 2 or 3 times a week and my mum cooks the other days.
- I like to drink proper coffee, with milk, no sugar...I'm sweet enough, I drink far too many cups each day at work, I try to detox from it on a weekend.
- Fairness, in every walk of life wherever you are from, whatever colour, creed or religion you may be.
- Doing a good job and being valued for the contribution I make.

### How best to support me...

- I prefer emails rather than telephone calls largely because if it's not written down I forget to do it (though I do like to talk).
- Praise, or constructive feedback, I don't like to feel as though I am failing and react far better to people telling me how things can be improved rather than what is wrong with my work.
- Be honest with me...if you don't like it say so.
- Let me get on with it...I like to get on with things free of interference I am capable of getting on with the job in hand, I don't need someone looking over my shoulder all of the time
- Give me solutions not problems.
- Don't be serious all of the time - a little light humour to lighten the mood never goes a miss.
- If you say you will do something please do it - or let me know as soon as possible why it cannot be done.
- Value me!
- Smile - apparently it's contagious ☺

# Coproduction Volunteers



# Coproduction volunteer role

- Volunteering as a Macmillan Joining the Dots County Durham Coproduction member **provides the chance to influence future ways of working** to ensure people affected by cancer are able to easily access support services in the community to address individual needs.
- The role of a Coproduction member is to:
  - **attend a monthly coproduction group meeting** (meetings are two hours long and are usually held during the day, although this may be changed if the majority of members would find it more convenient);
  - **apply their knowledge and personal experience** of being affected by cancer to improve access to social and community support;

# Coproduction volunteer role

- **Support activities** of Joining the Dots, such as our programme of **out-reach work, our community signposting or events** we host within local geographical communities and hard to hear communities;
  - help **monitor the project's progress** and **approve action plans** for future work;
  - take part in relevant **training sessions**.
- Benefits of becoming a coproduction member include **training and support** and the chance to **influence** how local community and social support for people affected by cancer are accessed in the future. **Out of pocket expenses** incurred will be reimbursed, see Durham County Council's expenses policy for more details.

# Ground rules

- Plain speaking/English
- Sensitive
- Everybody's opinion is valuable
- Realistic e.g. financial constraints
- 'Car park' for...
- No such thing as a stupid question
- Open minded
- Informal
- Respect

## Purpose

The Macmillan Joining the Dots Coproduction Group has been established to bring Durham County Council and Macmillan Cancer Support together with stakeholders and people who have been affected by cancer (coproduction volunteers) to design new ways of working to make sure people affected by cancer have easy, consistent and clear access to support around their holistic (e.g. practical, financial, emotional, spiritual, lifestyle) needs.

## Objectives

The members of the Coproduction Group will work together, **as equal partners** to:

- Consider existing information collected through local engagement activities (i.e. survey, one-to-one interviews and Joining the Dots events)
- **Discuss and debate** how to improve access to support for holistic needs
- **Determine options** for how the new ways of working could be put into practice
- Assist the project manager in costing the options for new ways of working
- To **identify a preferred option** for future ways of working
- Assist the project manager to develop a report based upon the preferred option for future ways of working



## Membership

The membership will consist of:

- At least 4 Coproduction volunteers
- 2 Joining the Dots Project staff
- 2 Durham County Council representatives
- 2 Macmillan Cancer Support representatives
- 2 CCG representatives
- 2 Hospital Trust representatives

## Governance

- The Coproduction Group will report to the Macmillan Joining the Dots Programme Board through the co-chairs.

## Quoracy

- In order to be quorate the meetings should have **no less than one third of the attendees as Coproduction volunteers**. There should be at least 1 member of the Joining the Dots project team and 1 member of Macmillan Cancer Support.

## Decision making

- Ideally a consensus of opinion will be achieved at the meeting. If a consensus of opinion cannot be achieved each person in attendance will receive a vote by way of a show of hands. All votes will receive equal status. The Chairs report to the Programme Board must reflect the opinion of all of the participants.

## Working Arrangements

- Meetings will be held on a monthly basis and will be 2-hours long
- Meetings will be held in an accessible venue with refreshments provided
- Meeting will take place in locations and at times that are mutually convenient
- Reasonable travel expenses will be reimbursed
- The group be co-chaired by the Joining the Dots Project Manager
- The group will elect a co-chair from the membership from the pool of volunteers
- An agenda for each meeting will be distributed in advance along with background documentation to aid understanding. Each member agrees to read all documents carefully and give full consideration to the items for discussion
- The meeting will be administered by Joining the Dots Project Support Officer
- Meetings will be attended by Durham County Council, Macmillan Cancer Support, North Durham and DDES Clinical Commissioning Groups, County Durham and Darlington Foundation Trust

# Celebration event at Durham Cathedral



# What do the volunteers think?

- *“It was daunting but it gives you a lot more confidence getting involved...You get involved because you are passionate”*
- *“There is a place for everyone”*
- *“Sometimes ordinary can become extraordinary”*
- *“Everyone has a contribution to make”*

# Reflections

<https://www.youtube.com/watch?v=BRNf4RR83JA&feature=youtu.be>

# What next for the volunteers?

- Scrutiny
  - Performance
  - Process
- Mentoring
- Mystery shopping
- Buddy
- Evaluation

# Lessons learnt

- Coproduction is doable
  - Power
  - Open & honest
- A different perspective
- Time
- Volunteers can be your biggest ally
- They are not unreasonable or unrealistic
- Hard but rewarding

