

Living with and beyond cancer Share & Learn

10th October 2018



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DRIVING
CHANGE
TOGETHER >

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Welcome

Introductions

Agenda



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Reflections

- We are half way through, making lots of progress, with lots to celebrate ... but there is still a long way to go.
- We are seeing sustained engagement and progress across the **8** CCG's localities & **6** acute trusts, through our **7** locality steering groups.
- We already know we are having an impact; we are seeing more people affected by cancer accessing support:
 - **over 900 additional** since we started in just 3/8 localities
 - **from 31% to 98%** of diagnosed patients in some tumour sites
 - **from 24% to 75%** of diagnosed patients in across some localities
- This has only been possible due to the sustained effort, energy and support of over **200** professionals and PABC across the eight localities.



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LWABC NHSE Metrics & Temp check

Getting there but still not outcomes based – the ‘so what?’

			Note: If you are able to provide an estimate or exact number of tumour groups in each trust using these interventions, this would be helpful but not essential.							
Name and contact details of person completing this spreadsheet	Name of Alliance	Name of Trust	Does this trust offer HNA in at least 1 tumour group?	Does this trust offer personalised care and support planning in at least 1 tumour group?	Does this trust offer treatment summaries in at least 1 tumour group?	Does this trust offer health and wellbeing events/courses/support in at least 1 tumour group?	Does this trust have protocols for stratified follow up in colorectal cancer?	Does this trust have protocols for stratified follow up in prostate cancer?	Does this trust have protocols for stratified follow up in any other cancer types	
Richard Metcalfe, Macmillan Programme Lead, Macmillan Living with and Beyond Cancer Programme, South Yorkshire and Bassetlaw Integrated Care System, richard.metcalfe1@nhs.net, (0114) 3051489	South Yorkshire, Bassetlaw & North Derbyshire	Barnsley	3 (electronic tool moving in to delivery) plus most tumour sites offer paper HNA	3 (electronic tool moving in to delivery) plus most tumour sites offer paper Care Plans	In development (currently provided by Haematology in paper format)	Breast (Moving Forward) but additionally offered to all tumour sites through development and implementation of HOPE programme which is underway (5 courses in total have now been delivered)	Currently implementing	Currently implementing	Breast	
	South Yorkshire, Bassetlaw & North Derbyshire	Chesterfield	All tumours sites	All tumours sites	In development	Breast, all other tumour sites to be piloted October 2018			Breast	
	South Yorkshire, Bassetlaw & North Derbyshire	Doncaster	3	3	In development	Breast	Currently implementing	Currently implementing	Breast	
	South Yorkshire, Bassetlaw & North Derbyshire	Rotherham	3	3	In development	Breast			Breast	
	South Yorkshire, Bassetlaw & North Derbyshire	Sheffield	3	3	Breast & Colorectal	All tumour sites		Currently implementing	Breast	
	West Yorkshire/part of SY LWABC programme	Wakefield	5	3	3	Breast	Currently implementing		Breast & Gynae	
	South Yorkshire, Bassetlaw & North Derbyshire	Community providers								
		Doncaster - Living well		All tumours sites	All tumours sites	N/A		N/A	N/A	N/A
	Bassetlaw - Aurora		All tumours sites	All tumours sites	N/A		N/A	N/A	N/A	

Looking forwards – building the evidence base

Rank	Bassetlaw	Doncaster	North Derby. & Hardwick
1	Physical concern Tired, exhausted or fatigued/sleep	Practical concern Finance	Emotional concern Thinking about the future
2	Family concern Children & Partner	Physical concern Eating/Appetite/Diet/ Nutrition	Emotional concern Anxiety/Worry
3	Emotional concern Sadness or depression	Family concern Children & Partner	Emotional concern Uncertainty
4	Emotional concern Thinking about the future	Practical concern Travel	Physical concern Tired, exhausted or fatigued/sleep
5	Practical concern Finance	Practical concern Mobility	Physical concern Eating/Appetite/Diet/ Nutrition

LWABC Programme Evaluation Framework

Overview and update

Share and Learn October 2018

Sarah Allen – Macmillan Senior Evidence Officer



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How did we get here?

Theories of change
for RP components



National Recovery
Package Outcomes
Framework



'Final' set of
programme
outcomes



Locality validation,
identification of
variance /change
statements



Validation of
core
monitoring
metrics



Programme
evaluation
framework



Locality evaluation
plans



Next steps.....

Common model in 'place based' solutions

Person centred conversations, with a meaningful shared care plan

linking people to the support they need in their community

- eHNA/**HNA** around the time of diagnosis and/or time of treatment
- based on the Macmillan concerns checklist
- CNS and/or CSW play a key role in starting, completing or working with a 'Hub' to complete the care plan.
- Appropriate **Risk stratification** agreed

- HNA and/or care plan is shared along with a **Treatment summary**
- Shared with Primary care to inform the **Cancer Care Review**

Community 'Hub' Information and support services

- Some play a role in eHNA/HNA and care planning
- Signposting/onwards referral
- Direct service provision
- MISS in some localities

Community support services

- Care plan results in signposting/onwards referral straight to a community service



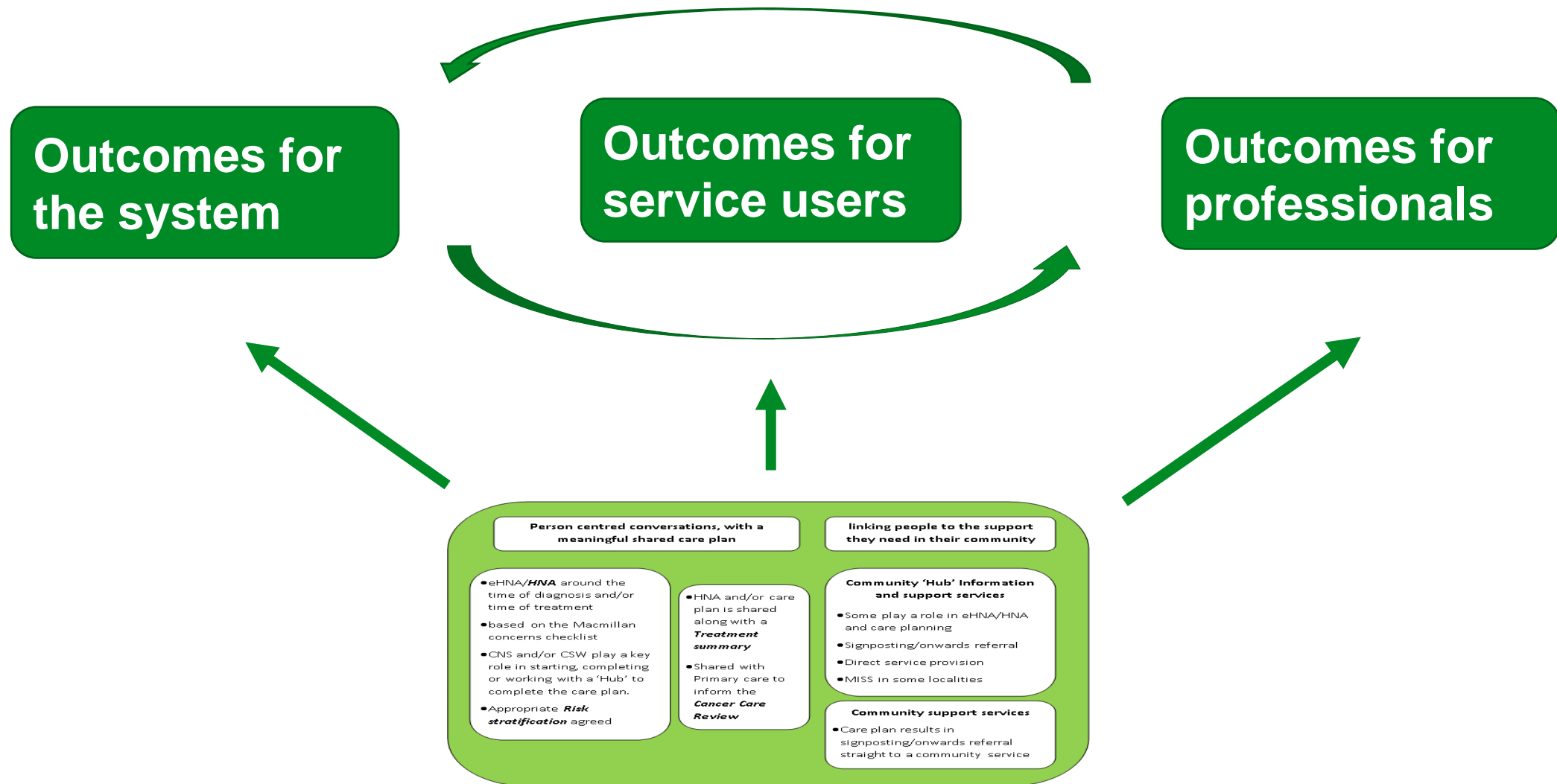
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Outcomes that we expect to see:



What questions are we trying to answer?

What works, for whom, in what context – and why?

- Are the **expected outcomes** of the LWABC model realised?
- What is the **effect of the variation** in context and delivery?
- Do different **people benefit differently**?
- What can we learn about **effective ways to implement** the model (and sustain, scale up)?

LWABC programme evaluation

Programme Evaluation (Outcomes) Framework

Core monitoring metrics

Locality evaluation plans

- Outcomes linked to the programme framework
- What additional/different we need to collect in different sites - variance

Structure and content of programme evaluation framework:

**Outcomes for
the system**

**Outcomes for
service users**

**Outcomes for
professionals**

Structure and content of framework (2)

Outcome (questions)	How will we know (measure/metric)	Tool/who/when etc		
1.3. People identify and talk about issues that are important to them – and they are prioritised and addressed as they change over time				
Q Did they feel able to talk about.... (why/why not)	- Patient experience	- Patient survey and SSIs		
Q Were their issues addressed (why/why not)	<ul style="list-style-type: none"> - Patient experience - Concerns raised vs concerns addressed 	<ul style="list-style-type: none"> - Patient survey, SSIs - Audit of HNAs and care plans - Staff SSIs 		

Structure and content of framework (3):

Principal tools / data sources:

- Electronic HNA data and other service data
- Patient and staff surveys
- Interviews (SSIs) with patients, staff and programme stakeholders

Each tool assesses multiple outcomes.....!

Next steps

External evaluator (Brightpurpose) – inception:

- familiarising with localities (variance mapping)
- refinement of evaluation framework and developing tools
- reviewing existing data and gaps (baseline)
- planning first rounds of data collection.....

Evaluation outputs and learning cycles

- Refined evaluation framework and tools (Nov/Dec)
- Baseline report (Jan)
- Interim report (June 2019)
- **Share and Learn Oct 2019**
- Interim report Feb 2020
- **Share and Learn Oct 2020**
- Final report Nov 2020



PERSONALISING CARE FOR PEOPLE LIVING
WITH CANCER

LEARN AND SHARE EVENT

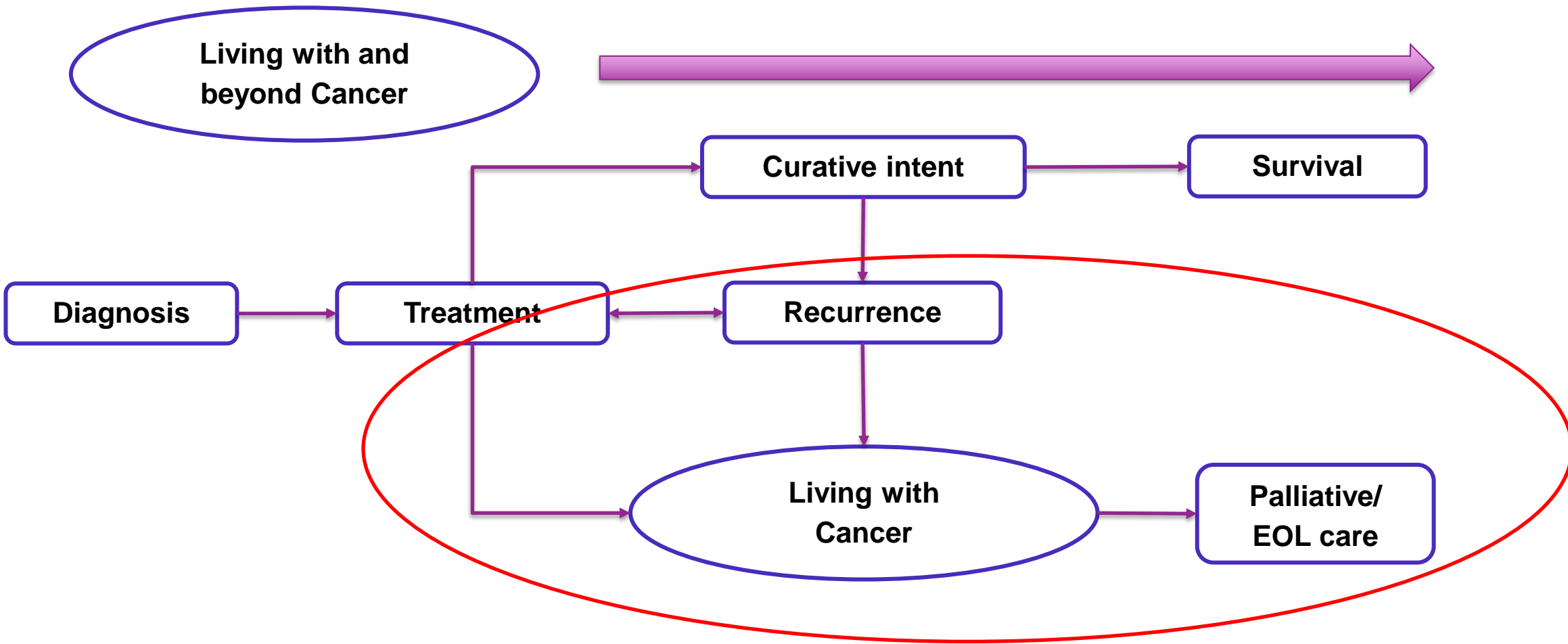
10 October 2018

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The brief

- ★ Start a conversation about streamlining and personalising care for people living with cancer
 - What works well now?
 - What could be better?
 - What skills and competencies matter when supporting people at this stage in their care?

Living with cancer definition

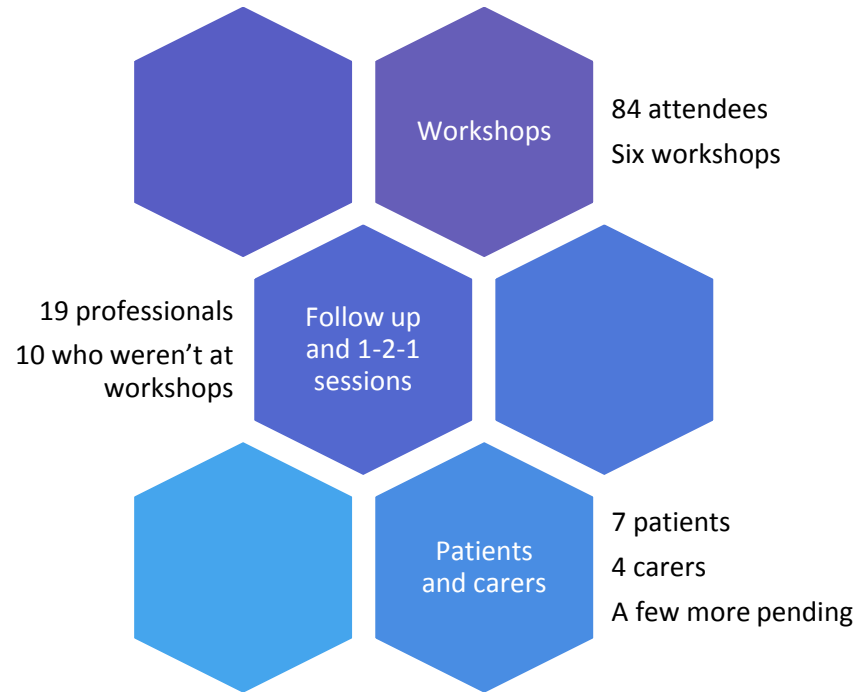


Framing the conversation

The commitment to end the variation in end of life care across the health care system by 2020 so that people approaching the end of their lives:

- ★ have **honest discussions** with care professionals about their needs and preferences
- ★ make **informed choices** about their care
- ★ develop and document a **personalised care plan**
- ★ **discuss** their personalised care plans with care professionals
- ★ **involve** their family, carers and those important to them in all aspects of their care as much as they want
- ★ **know who** to contact for help and advice at any time

Who has been part of the conversation?



Strong representation from acute, community nursing, hospice, palliative, CCG and Macmillan teams
Less representation from primary care, voluntary sector, care home and children and young people teams



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What we found

First things first...

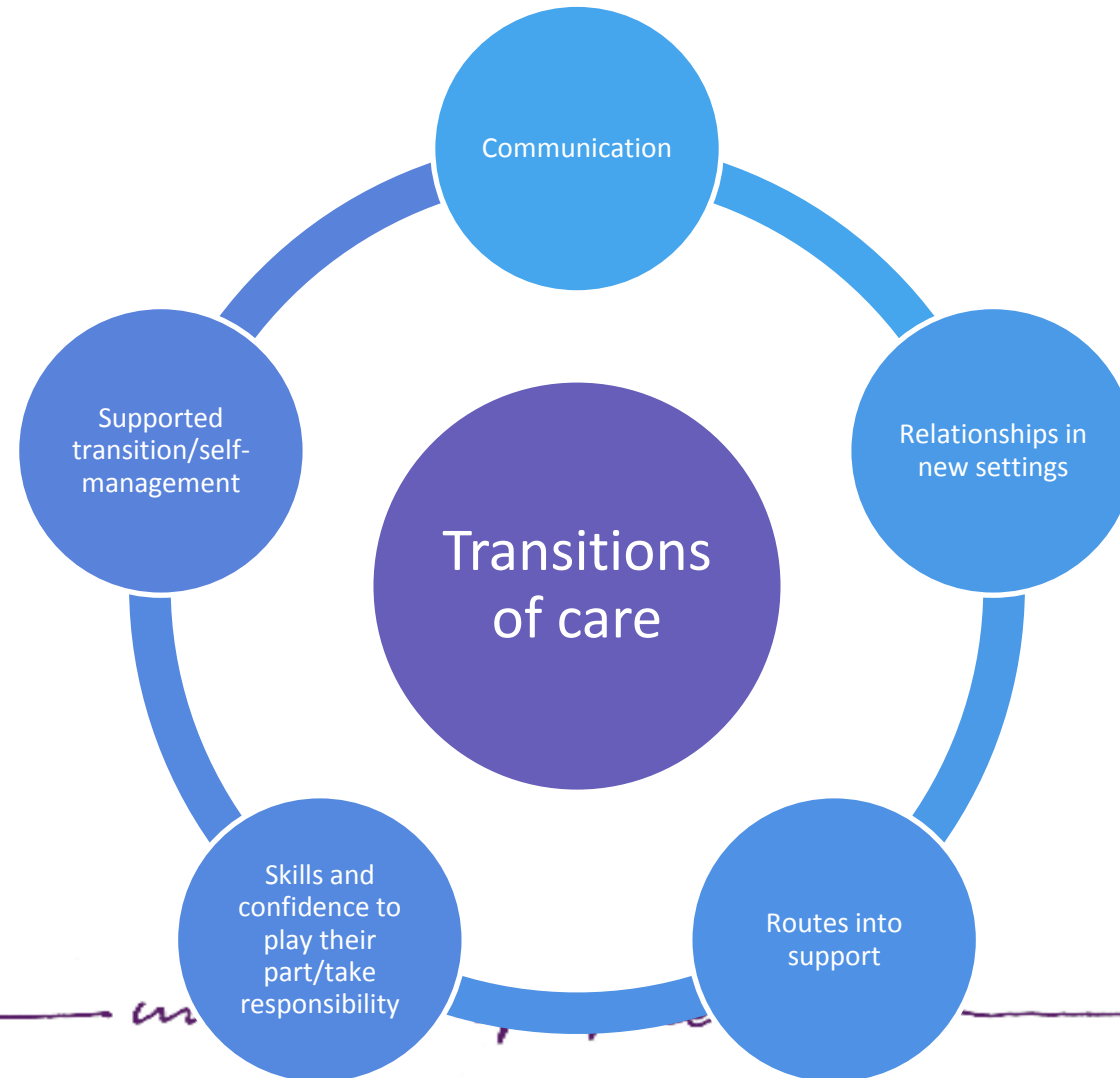
- ★ Overall, the system is working well
- ★ Professionals are committed to personalising care as much as possible for patients and their carers
- ★ Some things get in the way, and cause frustrations for patients AND professionals
- ★ That's what we'll focus on today

- ★ But remember – this is not a broken system, it's one that could be further improved

Different systems, similar challenges

- ★ Systems and local assets vary
- ★ Issues similar across all the localities
- ★ And similar to those we see in other parts of the UK
- ★ Responses to the issues need to fit the locality

Improving personalised care for people living with cancer



Enablers and barriers

★ Barriers

- Time
- Siloed resources

★ Enablers

- People
- Conversations
- Process, but not by itself
- How you use your time and skills – and the permission to use them in different ways

Lots of commonality with the rest of the LWABC pathway

- ★ It's all about the conversation
 - With a trusted person
 - Who can connect you to the support you need
- ★ Also lays the foundation for timely advanced care planning
- ★ The context and level of patience may be different but the issues are the same

Applicable existing practice

Communication

- EPaCCS
- Red book
- Neighbourhood teams (the way they work, not the structure themselves)

Relationships

- Support worker/navigator
- Neighbourhood teams

Routes into support

- HNA
- Support worker/navigator

Skills and knowledge

- Care home training

Supported transition/self-management

- Community matrons – intensive transition support

Hmmm... interesting

- ★ Some of the barriers are unlikely to change
- ★ This seems to be partly about how people work together and individually
 - How they use their time
 - How they collaborate
- ★ Some of the solutions might be a bit old-school and low-tech – and that's OK
- ★ Some will be cultural (permission)
- ★ Some involve resource, eg navigators/support workers

Questions?

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Discussion points

1. Your reflections on what we've found?
2. Where should we start?
3. What could you take away and change tomorrow?
4. What should be the top three priorities for moving this forward in your area?