Living with and beyond cancer
Share & Learn
10th October 2018
Welcome

Introductions

Agenda
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:
  o **over 900 additional** since we started in just 3/8 localities
  o **from 31% to 98%** of diagnosed patients in some tumour sites
  o **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.
## LWABC NHSE Metrics & Temp check

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

<table>
<thead>
<tr>
<th>Name and contact details of person completing this spreadsheet</th>
<th>Name of Alliance</th>
<th>Name of Trust</th>
<th>Does this trust offer HNA in at least 1 tumour group?</th>
<th>Does this trust offer personalised care and support planning in at least 1 tumour group?</th>
<th>Does this trust offer treatment summaries in at least 1 tumour group?</th>
<th>Does this trust offer health and wellbeing events/courses/support in at least 1 tumour group?</th>
<th>Does this trust have protocols for stratified follow up in colorectal cancer?</th>
<th>Does this trust have protocols for stratified follow up in prostate cancer?</th>
<th>Does this trust have protocols for stratified follow up in any other cancer types</th>
</tr>
</thead>
<tbody>
<tr>
<td>Richard Metcalfe, Macmillan Programme Lead, Macmillan Living with and Beyond Cancer Programme, South Yorkshire and Bassetlaw Integrated Care System, <a href="mailto:richard.metcalfe1@nhs.net">richard.metcalfe1@nhs.net</a>, (0114) 3051489</td>
<td>South Yorkshire, Bassetlaw &amp; North Derbyshire</td>
<td>Barnsley</td>
<td>3 (electronic tool moving in to delivery) plus most tumour sites offer paper HNA</td>
<td>3 (electronic tool moving in to delivery) plus most tumour sites offer paper Care Plans</td>
<td>In development (currently provided by Haematology in paper format)</td>
<td>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)</td>
<td>Currently implementing</td>
<td>Currently implementing</td>
<td>Breast</td>
</tr>
<tr>
<td></td>
<td>South Yorkshire, Bassetlaw &amp; North Derbyshire</td>
<td>Chesterfield</td>
<td>All tumours sites</td>
<td>All tumours sites</td>
<td>In development</td>
<td>Breast, all other tumour sites to be piloted October 2018</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>South Yorkshire, Bassetlaw &amp; North Derbyshire</td>
<td>Doncaster</td>
<td>3</td>
<td>3</td>
<td>In development</td>
<td>Breast</td>
<td>Currently implementing</td>
<td>Currently implementing</td>
<td>Breast</td>
</tr>
<tr>
<td></td>
<td>South Yorkshire, Bassetlaw &amp; North Derbyshire</td>
<td>Rotherham</td>
<td>3</td>
<td>3</td>
<td>In development</td>
<td>Breast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>South Yorkshire, Bassetlaw &amp; North Derbyshire</td>
<td>Sheffield</td>
<td>3</td>
<td>3</td>
<td>Breast &amp; Colorectal</td>
<td>All tumour sites</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>West Yorkshire/part of SY LWABC programme</td>
<td>Wakefield</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>Breast</td>
<td>Currently implementing</td>
<td></td>
<td>Breast &amp; Gynae</td>
</tr>
<tr>
<td></td>
<td>South Yorkshire, Bassetlaw &amp; North Derbyshire</td>
<td>Community providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Doncaster - Living well</td>
<td>All tumours sites</td>
<td>All tumours sites</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bassetlaw - Aurora</td>
<td>All tumours sites</td>
<td>All tumours sites</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

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.
<table>
<thead>
<tr>
<th>Rank</th>
<th>Bassetlaw</th>
<th>Doncaster</th>
<th>North Derby. &amp; Hardwick</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Physical concern</td>
<td>Practical concern</td>
<td>Emotional concern</td>
</tr>
<tr>
<td></td>
<td>Tired, exhausted or fatigued/sleep</td>
<td>Finance</td>
<td>Thinking about the future</td>
</tr>
<tr>
<td>2</td>
<td>Family concern</td>
<td>Physical concern</td>
<td>Emotional concern</td>
</tr>
<tr>
<td></td>
<td>Children &amp; Partner</td>
<td>Eating/Appetite/Diet/Nutrition</td>
<td>Anxiety/Worry</td>
</tr>
<tr>
<td>3</td>
<td>Emotional concern</td>
<td>Family concern</td>
<td>Emotional concern</td>
</tr>
<tr>
<td></td>
<td>Sadness or depression</td>
<td>Children &amp; Partner</td>
<td>Uncertainty</td>
</tr>
<tr>
<td>4</td>
<td>Emotional concern</td>
<td>Practical concern</td>
<td>Physical concern</td>
</tr>
<tr>
<td></td>
<td>Thinking about the future</td>
<td>Travel</td>
<td>Tired, exhausted or fatigued/sleep</td>
</tr>
<tr>
<td>5</td>
<td>Practical concern</td>
<td>Practical concern</td>
<td>Physical concern</td>
</tr>
<tr>
<td></td>
<td>Finance</td>
<td>Mobility</td>
<td>Eating/Appetite/Diet/Nutrition</td>
</tr>
</tbody>
</table>
LWABC Programme Evaluation Framework

Overview and update

Share and Learn October 2018
Sarah Allen – Macmillan Senior Evidence Officer
How did we get here?

Theories of change for RP components → National Recovery Package Outcomes Framework → ‘Final’ set of programme outcomes

Programme evaluation framework → Validation of core monitoring metrics → Locality validation, identification of variance/change statements

Locality evaluation plans → Next steps…. 
Common model in ‘place based’ solutions

Person centred conversations, with a meaningful shared care plan

- 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

Linking people to the support they need in their community

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
Outcomes that we expect to see:

Outcomes for the system

Outcomes for service users

Outcomes for professionals

- Person-centred conversations, with a meaningful care plan
  - HCPs around the time of diagnosis and/or treatment
  - Based on the Macmillan cancer checklist
  - CNS and/or ClsM play a key role in planning, completing, or working with a 'link' to complete the care plan
  - Appropriately seek-stratification agreement

- Linking people to the support they need in their community
  - Community 'Hub': information and support services
    - Some pay a role in HCP/PhA care planning
    - Signposting/forward referral
    - Counselling provision
    - Mac in some localities

- Community support services
  - Care plan results in signposting/referral to local community service
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)?
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)

<table>
<thead>
<tr>
<th>Outcome (questions)</th>
<th>How will we know (measure/metric)</th>
<th>Tool/who/when etc</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.3. People identify and talk about issues that are important to them – and they are prioritised and addressed as they change over time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q Did they feel able to talk about…. (why/why not)</td>
<td>Patient experience</td>
<td>Patient survey and SSIs</td>
</tr>
<tr>
<td>Q Were their issues addressed (why/why not)</td>
<td>Patient experience</td>
<td>Patient survey, SSIs</td>
</tr>
<tr>
<td></td>
<td>Concerns raised vs concerns</td>
<td>Audit of HNAs and care plans</td>
</tr>
<tr>
<td></td>
<td>addressed</td>
<td>Staff SSIs</td>
</tr>
</tbody>
</table>
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
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

Living with and beyond Cancer

Diagnosis → Treatment → Recurrence

Curative intent → Survival

Living with Cancer

Palliative/EOL care
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?

84 attendees
Six workshops

19 professionals
10 who weren’t at workshops

Follow up and 1-2-1 sessions

7 patients
4 carers
A few more pending

Patients and carers

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
THANK YOU!
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
Transitions of care

Communication

Supported transition/self-management

Relationships in new settings

Skills and confidence to play their part/take responsibility

Routes into support

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

<table>
<thead>
<tr>
<th>Communication</th>
<th>Relationships</th>
<th>Routes into support</th>
</tr>
</thead>
<tbody>
<tr>
<td>• EPaCCS</td>
<td>• Support worker/navigator</td>
<td>• HNA</td>
</tr>
<tr>
<td>• Neighbourhood teams (the way they work, not the structure themselves)</td>
<td>• Neighbourhood teams</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skills and knowledge</th>
<th>Supported transition/self-management</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Care home training</td>
<td>• Community matrons – intensive transition support</td>
</tr>
</tbody>
</table>
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?
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?