Dany Bell
Macmillan National Programme
Lead Treatment and Recovery
<table>
<thead>
<tr>
<th>I was diagnosed early</th>
<th>I understand, so I make good decisions</th>
<th>I get the treatment and care which are best for my cancer, and my life</th>
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<tbody>
<tr>
<td>Those around me are well supported</td>
<td>I am treated with dignity and respect</td>
<td>I know what I can do to help myself and who else can help me</td>
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<tr>
<td>I can enjoy life</td>
<td>I feel part of a community and I'm inspired to give something back</td>
<td>I want to die well</td>
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Implementing Recovery Package and Stratified Pathways:
A case Study of implementing the Recovery Package at North Bristol NHS Trust
Where did we start?
The impact of cancer and treatment

Patient Reported Outcome Measures (PROMS) give insight to:

• the quality of life for those living with and beyond cancer from their experiences and point of view

• the impact of cancer and treatments on ability to lead meaningful lives.
What did people tell us?

• 1 year post diagnosis nearly half feared recurrence and almost a third were afraid of dying.
• 38% of prostate cancer survivors reported urinary leakage and 58% reported impotence.
• 1 in 5 colorectal survivors had difficulty in bowel control.
• QOL is closely associated with disease status and presence of other long term conditions.
• Almost a third reported doing no physical activity and around a fifth did the weekly recommended CMO physical activity i.e. 30 mins x 5.
• Increased physical activity associated with better QOL.
### Consequences of treatment

Matching services to the numbers of risk

<table>
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<tr>
<th>Hundreds of people</th>
<th>Severe, complex late effects</th>
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<tr>
<td>Tens of thousands</td>
<td>Consequences ranging from mild to severe e.g. Bowel, urinary and sexual problems</td>
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<tr>
<td>Hundreds of thousands</td>
<td>Increased risk of future problems e.g. CVD &amp; osteoporosis</td>
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Aligning with the NHS Mandate in England

- Providing safe care
- Helping people live longer
- Helping people manage their ongoing physical and mental health conditions
- Helping people recover from episodes of ill-health or injury
- Making sure people experience better care
What did we do?
Implemented self management education and support programme:

- Living Well days 4-6 months post treatment
- Living Well course 9 months post treatment
- Post treatment exercise programme
- Dietetic support

Implemented stratified follow-up
- Teams stratified patients to a red, amber or green pathway

Developed a care management system
- To undertake remote surveillance and reduce follow up

Pilot site for electronic Health Needs Assessment
Then What?

• Asked our Users
• Talked to commissioners
• Scoped what was happening
• Identified our champions
• Formed a steering group
• Put on Trust Board and Cancer Board work programmes
Breast

400 new cases/year
November 2010- Stopped routine surgical follow-up
Nurse Led:

‘Look After Yourself’ event at 4-6 months
Living Well Course (SMP) at course 9 months
HNA and care plan by CNS
Open access appointments
Mammogram surveillance
Breast Team:

• Very experienced CNS and manager

• Cohesive team

• Had already implemented redesign

• Follow up already reduced and predominantly nurse led
350 new cases/year
December 2010 surgical follow up reviewed:

6 week post op review by CNS
Living Well event at 4-6 months
Living Well course at 9 months
2 years stable disease moved to green pathway
CEA, CT, Colonoscopy remote surveillance
Colorectal Team;

• Dynamic

• All routine follow-up nurse led except for 1 consultant!

• Requesting diagnostics

• However, no support group and very sceptical!
Prostate

500 new cases/year
December 2010 surgical follow up reviewed:

- 2 week post op review by CNS
- HNA and care plan at CNS 6/52 OPA
- Living Well event 4-6 months
- Living Well course 9 months
- 2 years stable disease moved to green pathway with PSA remote surveillance
- Discharging from lifetime and 5 year follow-up with open access
Prostate Team:

- Dysfunctional appeared over stretched with workload, failing targets
- Reconfiguration across city
- New consultant experienced with remote surveillance
- 1 out of the 4 CNS’s enthusiastic
- Directorate manager supportive
% patients moved to an alternative pathway (amber or green)

Colorectal 95%
Prostate 60%
Breast 98%
Progress after 1 year:

- All 9 cancer MDT teams providing Living Well events with information and practical advice to enable supported self management with increased patient participation
- Living Well self management course for Breast piloted
- Routine follow-up for breast for newly diagnosed ceased
- Living Well course for Prostate developed
- Telephone follow up replacing face to face
- Developed Red/Amber/Green pathways with clinical teams
- Breast Team piloted needs assessment
Progress after 2 years:

- Successful implementation of stratified follow-up and remote monitoring for patient follow-up in breast, colorectal & prostate
- Telephone and remote surveillance clinics commissioned
- Development of electronic tracking system for remote surveillance
- Programme of training undertaken for CNS’s
- Physical activity programme piloted
- Colorectal, Prostate, Upper GI, using paper based HNA
- All Patient information reviewed
- Won Trust Excellence award for best service improvement
Progress after 3 years:

- Programme of training for lay tutors with active user involvement in Living Well programmes
- Living Well Self management course for colorectal developed
- eHNA pilot site in breast, prostate, colorectal
- Breast team starting to use electronic treatment summary in Somerset Cancer Register
- Whole health community bid put in for 1:1 pilots
- Won best adult poster at end of NCSI programme
Progress year 4

• CBT training offered to all staff involved in cancer care improving confidence
• Extension of Macmillan electronic health needs assessment (eHNA) to all tumour sites
• Exercise and Nutrition outpatient clinics. Partnership working with local leisure centres and physiotherapy department
• Trial of new roles to support patients living with and beyond cancer - Macmillan 1:1 project (Bristol city wide collaborative partnership)
• Shifting to the community
North Bristol’s Recovery Package Model

- Living Well events
- Self Management programmes
- E-HNA
- Macmillan One to One
- Remote Monitoring
- Nutrition clinic
- Exercise programme

NBT Recovery Package
What helped?

• Trust Board support and an executive sponsor
• Dedicated nursing lead for survivorship
• Good admin support – dedicated time
• Support from Macmillan – financial and practical
• Training for staff in CBT (level II psychology)
• Engagement with and involvement of users, AHP’s etc
• Funding for venues and catering
• Use of champions to motivate others
• Positive patient feedback
• Engagement of medical colleagues
<table>
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<tr>
<th>Challenges - Staff</th>
<th>Challenges - Patients</th>
<th>Challenges - Environment</th>
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<tr>
<td>A willingness to try out changes to the traditional models of working overcoming</td>
<td>To accept increased responsibility for self care and</td>
<td>Improving information relay across organisational</td>
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<tr>
<td>perceived threats</td>
<td>possible lifestyle change</td>
<td>boundaries</td>
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<tr>
<td>Integrating care across organisational boundaries</td>
<td>Participating in clinics alongside other patients rather</td>
<td>Provider organisations setting aside competitive financial</td>
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<td></td>
<td>than one to one consulting</td>
<td>self interest to construct a multi-organisational model</td>
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<tr>
<td>Partnership working with external organisations</td>
<td>Increase requirement for self monitoring and feedback</td>
<td>IT challenges around eHNA and remote monitoring and</td>
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<td></td>
<td></td>
<td>accessing venues for Living Well events</td>
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<td>Accepting partnership working with patients using a collaborative method of</td>
<td></td>
<td>Commissioners acceptance of fluidity during the change</td>
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<tr>
<td>consulting</td>
<td></td>
<td>process</td>
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Patient Feedback

“The Living well day has given me more confidence to deal with day to day challenges that arise”

“Sharing the overall experience and feelings..... listening to others and how they have coped gave me comfort”

“it was not until it was all written down did I realise the only person who could make it happen was me. It was clearly there in black and white”

“So happy to have been able to attend. I did feel that void after my excellent care but now I have had help again”

“Really good to hear that my feelings are all normal and my experiences are shared by others”
Vision

Collaborative culture with empowered and informed patients taking active roles in their recovery

Individual HNA from the beginning of the pathway driving patient centred care

Implementation of the treatment summary across all tumour sites

Patient self management with open timely access to specialist support when required

Seamless care between specialist and community providers

Transparent evaluation and reporting of services using standardised measures of outcome and patient experience that reflect an exceptional level of care
2015 Vision

Established evidence based new cost effective pathways supporting long term recovery and health and wellbeing of patients affected by Cancer

An established survivorship structure from collaboration between NBT, community providers, commissioners, users, Macmillan and other third sector organisations

A new collaborative culture in which empowered and informed patients take more active roles in their recovery

Macmillan funded Wellbeing Centre co-ordinating all Living Well activities

Individual HNA from the beginning of the pathway driving patient centred care
What’s happening next?

Pan-Avon approach to sustainable commissioning
Improving communication and integration of services across secondary and primary care
Implementation of the treatment summary across all tumour sites
Collaborative cross-city working with UH Bristol and Penny Brohn Cancer Centre (joint programmes)
Continued redesign of patient pathways to improve experience and efficiency
Key survivorship messages

• The **Recovery Package** is key to good care and enables good communication across boundaries.

• A **shift in professional culture** is essential to enable supported self management.

• Many **people can self manage their health** with support, may need rapid access to professionals.

• **Significant need** arising from consequences of treatment can be prevented or treated.

• New models of cancer aftercare can **improve quality and reduce cost**.
Questions

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