St James's Institute of Oncology

The Leeds Teaching Hospitals NHS
NHS Trust

UNIVERSITY OF LEEDS

Community Follow-Up

after a Germ Cell Tumour

Oana Lindner, Carolyn Gosney, Diane Hubber, Jen Harding, Johnathan Joffe, Dan Stark

THE CRYSTAL EVENT

Follow-up after cancer treatment

Is

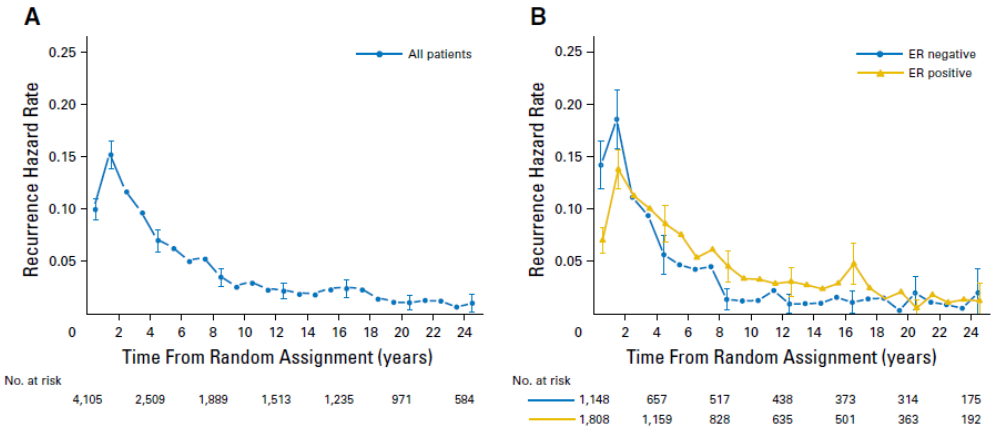
Continuing to provide clinical review for patients after cancer treatment

in order to

- Intervene if the cancer changes
- Manage toxicities of treatment
- Support people living after cancer

What are the problems with follow-up?

- Cancer can return, for many years after treatment
  - The yield of follow-up to detect recurrence reduces over time
- Therefore, pragmatic decisions about how to schedule follow-up



Breast cancer recurrence over time
Colleoni et al January 19, 2016, doi: 10.1200/JCO.2015.62.3504

Post-treatment surveillance approaches are imperfect

- Recurrence risk is clinically defined – site, size, surgery, biology – but not precisely
- Symptom reports vary between patients
- Symptom interpretation varies between clinicians (e.g. by patience, skill and experience)
- Imaging and biomarkers vary greatly e.g. Scans, blood markers (PSA), LFTs, CTCs (leukaemia)
- Trade offs
    - Interval of assessments vs negative predictive value, equivocal findings, false-positive test findings etc

Patients may prefer to remain in the cancer system

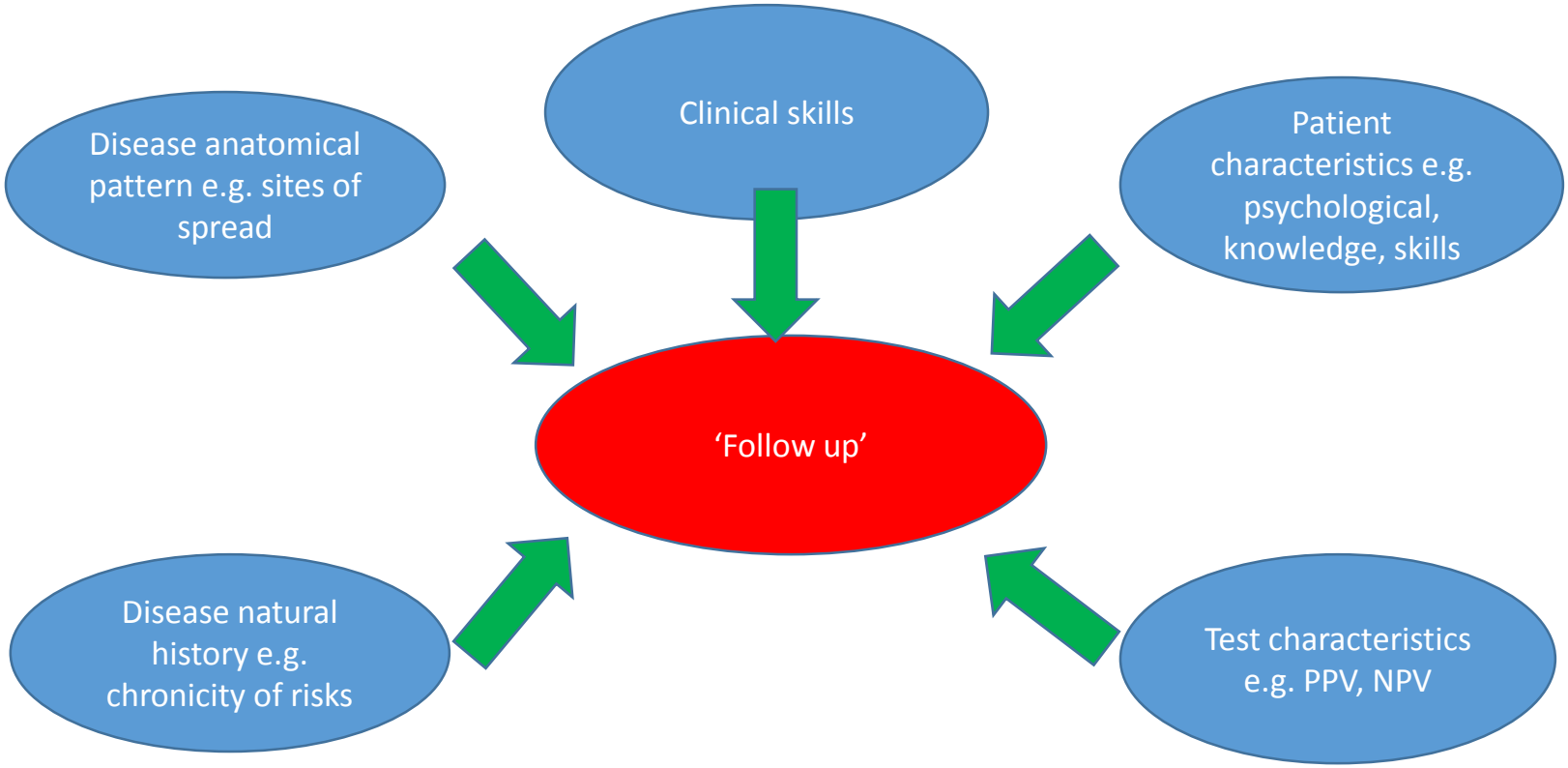
Health anxiety

Fear of recurrence

Trust in primary care systems

To optimise the management of any recurrence

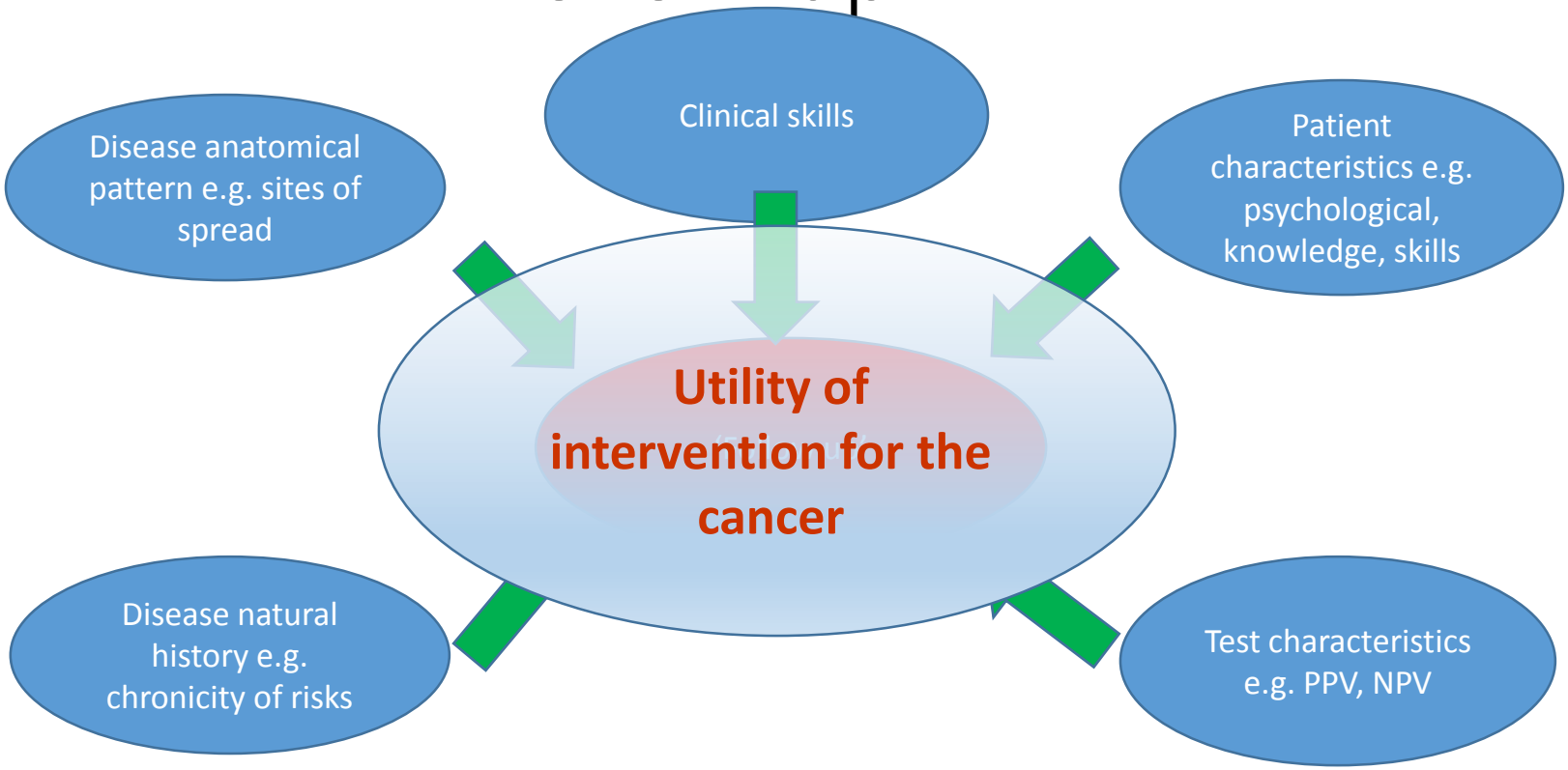
The nature of follow-up



In uncertainty about intervention

- Recurrence is often metastatic, but not always
- Metastatic return is usually incurable, but not always
  - Germ cell - odds of cure are high, although varying with the speed of the detection and the site of the recurrence

Factors determining the utility of clinical follow-up



Late effects of treatment
B) Psychological wellbeing

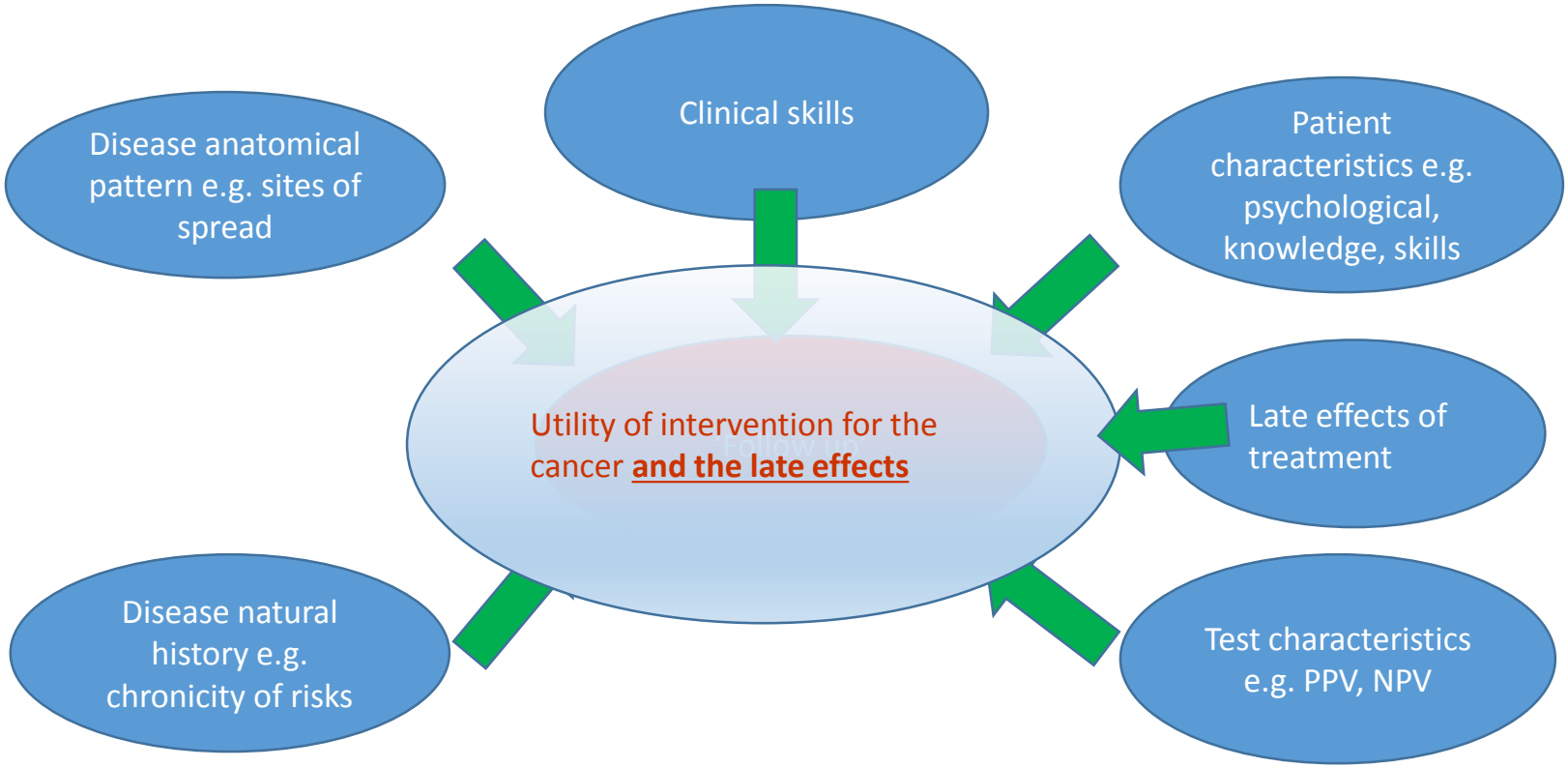
- 1408 Norwegian testicular cancer (TC) survivors - anxiety disorders remain significantly more prevalent than general population after 11 years [1]
- More so when younger
- Patients interpret everyday bodily symptoms as indicating serious disease, worry, seek clinical reassurance, BUT are made more anxious and more dependent upon follow-up by non-specific reassurance[3].
- Contrasts with the approach taken for health anxiety in mental health settings.

Table 4. Adjusted Odds Ratio (OR) of Serious Psychological Distress (SPD) for Each Clinical and Sociodemographic Characteristic Among the Long-term Survivors of Adult-Onset Cancer

Variable	Sample Size[a]	SPD, %[b]	Adjusted OR (95% CI)[c]
Age at interview, y			
<45	578	10.7	5.6 (3.3-9.5)
45-64	1629	6.7	2.7 (1.8-4.0)
≥65	2429	3.2	1 [Reference]

1. Dahl J Clin Oncol. 2005;23:2389-2395; 2. Hoffman J Natl Cancer Inst Monogr. 2010; 3. Stark BJC 2004

The nature of follow-up



Follow-up after cancer is resource intensive

- 2.4 million NHS follow-up appointments in oncology in 2011/12 (HES online)
- Not evidence based in their planning, not optimised in their focus, delivered variably in quality
- Multiple purposes – recurrence, psychological care, physical late effects, broader 'survivorship' elements
  - Return to productive socially integrated lives, quality of life
  - Regain trust in some clinical systems after diagnostic pathways

Models of follow-up care

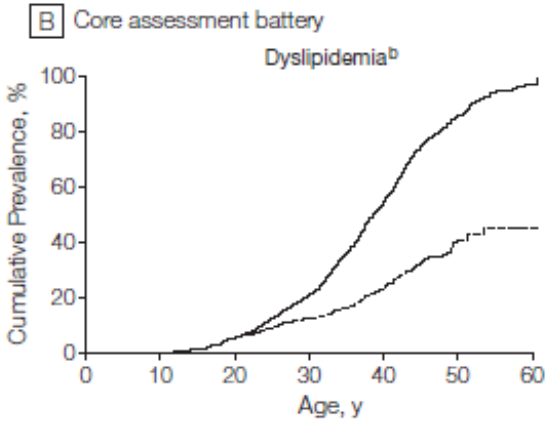
- Traditional Vs shared-care Vs nurse-led Vs self-management Vs GP

Level	Treatment	Follow Up	Frequency
1	Surgery alone Low risk chemotherapy	Postal or telephone	1-3 years
2	Chemotherapy Low-dose cranial irradiation (<24 Gy)	Nurse-led or primary care	1-2 years
3	Radiotherapy (>24Gy) Megatherapy	Medically supervised LTFU clinic	1-2 yearly

UKCCSG

Q: Are GPs well placed to run cancer follow-up?

- **A**: not at present
- But…they are seeing cancer survivors of all ages
  - 1157 Canadian survivors diagnosed before age 20[1]
    - 97% saw at least 1 GP in a 3-year period
    - Primary care visits more likely once aged >20 years.
- GP care appears not be detecting the problems
  - Under-diagnosis by age 35 is substantial for asymptomatic disease such as dyslipidaemia, cardiac valvular disease, and hearing loss[2]
- But neither are the traditional models for some problems
  - Most second cancers in long-term TGCT survivors are self-detected interval events during regular oncology follow-up[3]



1. McBride CAYACS Research Group; 2. Henderson JAMA 2013; 3. Buchler Cancer. 2011

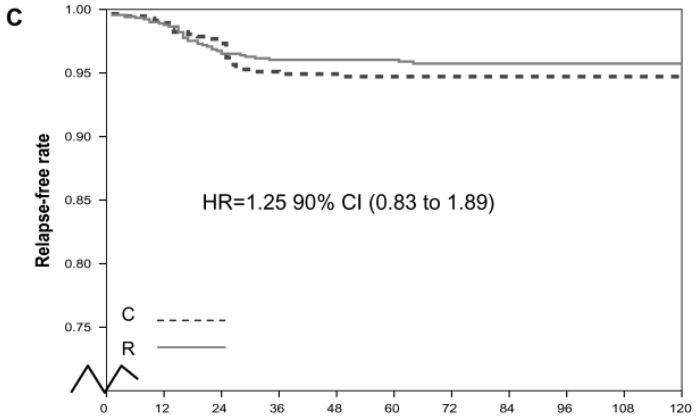
Summarise

- Surveillance is useful
- Scheduling is variable
- Tests are imperfect
- Patients and clinicians are imperfect
- Purposes need to embrace psychosocial and survivorship aspects as well as cancer status and toxicity
- Best models are not certain

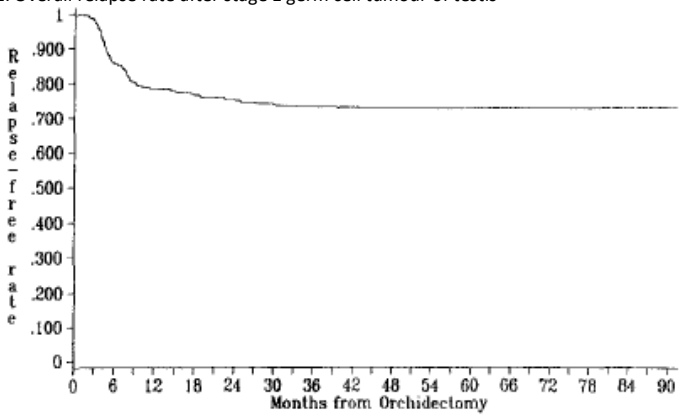
Germ cell tumour surveillance in Yorkshire

- Single regional oncology service across Yorkshire, travel up to 60 miles:
  - Surgery alone OR Surgery + chemotherapy/ Surgery+ chemotherapy+ radiotherapy
  - **Mediocre patient experience – 60 patients per week, 3 doctors, 2+ hour waits**
- Young, working/education/training
- Extensive use of surveillance in resected stage 1 disease
  - avoid unnecessary therapy
  - high stakes (up 50% risk of curable relapse)
- All surveillance types involve collection of:
  - Biomarkers – Very high sensitivity and specificity - alphaFP, betaHcG
  - Chest X-ray or CT
  - Clinical symptoms
- Surveillance for between 3 and 10 years
- Evidence
  - MRC dataset - mode & timing of detection of recurrence (1 - 3)
  - Flat curves for relapse after 5 years (1, 2)
- Characterised late effects
  - Second cancers, renal injury, IHD, anxiety
- **Work with PCOR group – Tracker for surveillance & Q-Tool for PRO capture**

1. Relapse-free rate in chemotherapy vs radiotherapy-treated patients up to 10-years post-treatment for stage 1 seminoma testis

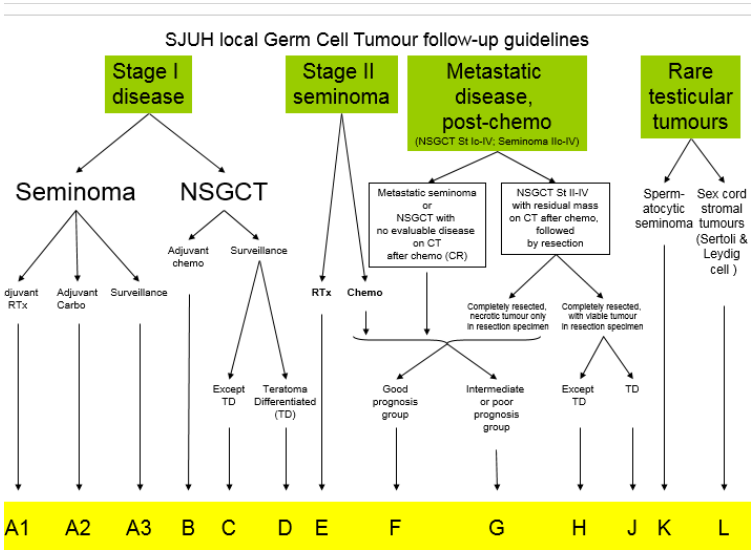


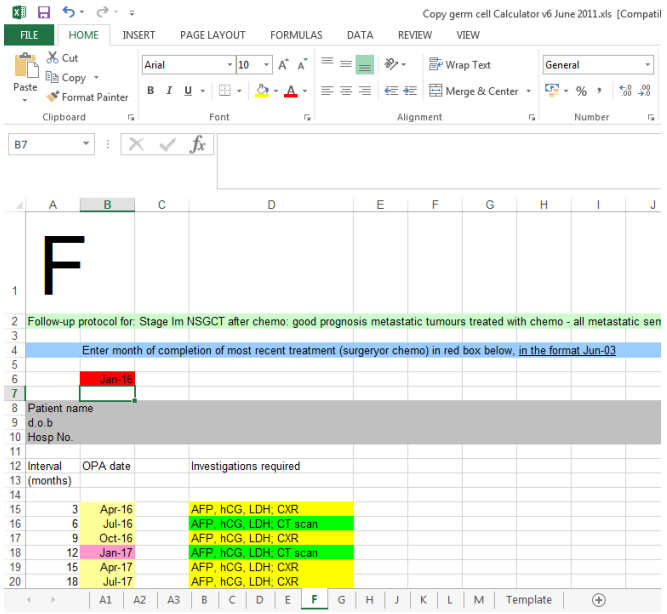
2. Overall relapse rate after stage 1 germ cell tumour of testis



1. Mead et al, JNCI 2011; 2. Read et al, JCO 1992; 3. Rustin et al JCO 2007

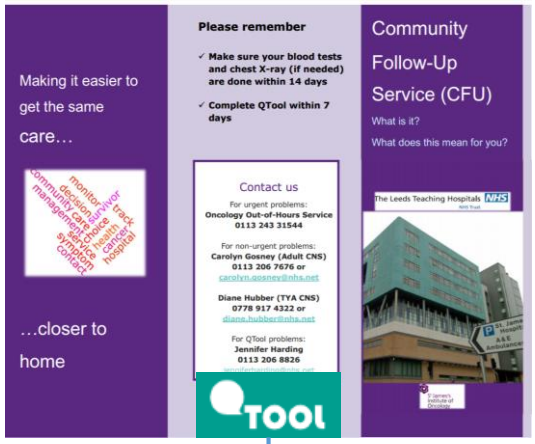
Structured evidence-based follow-up





Community Follow-Up

- Community Follow-up
  - Same intervals as for clinic, same tests
  - QTool instead of OPA Hx – broader (psychosocial and physical), consistently delivered
  - OPA face to face once per year or for CT results
  - Blood tests, X-rays - we provide test request cards
  - Care & test interpretation still specialist- many fewer OPA visits



Could we?

- Organise ourselves and the patients to have the **right tests** at the **right time** without the out-patient clinic to organise that in? → whole-system change
- **Estimate key symptoms** and **assess psychological well-being** and concerns using PROs online reliably compared to in clinics → professional change
- **Facilitate investigations** at **any** competent provider → system change
  - Flexibility where and when – GP, local hospital, supermarket
  - Often nearer home
- Identify the results and act upon them in a timely manner
  - **Communicate** this to the patient and involved clinicians → communication change

Without the patients coming to the clinic face to face (or at least much less often)?

Patients are open to change in services

- 4th year Medical Student Ravi Raja, 2011-12
- 33 patients over 2 weeks (39 approached) - all in Standard follow-up
  - 2/3 in favour of community follow-up in principle
    - No age effect
    - Leeds patients less in favour
  - Felt to reduce the time taken for clinic (travel + waiting)
  - Felt to reduce the impact upon work/education

Clinician consultation

- Might:
  - Encourage patients to take more responsibility for their tests, control of their health and self-manage
    - Self care education & health promotion necessary
- Enhance integrated care between Oncology, primary care and regional hospitals
- Needs:
  - Sufficient professional capacity, right skill-mix, IT linkage, education and training
  - Clear communication systems

Commissioner perspective

- Enthusiastic:

people with cancer come to cancer care right away, those no longer with cancer don't

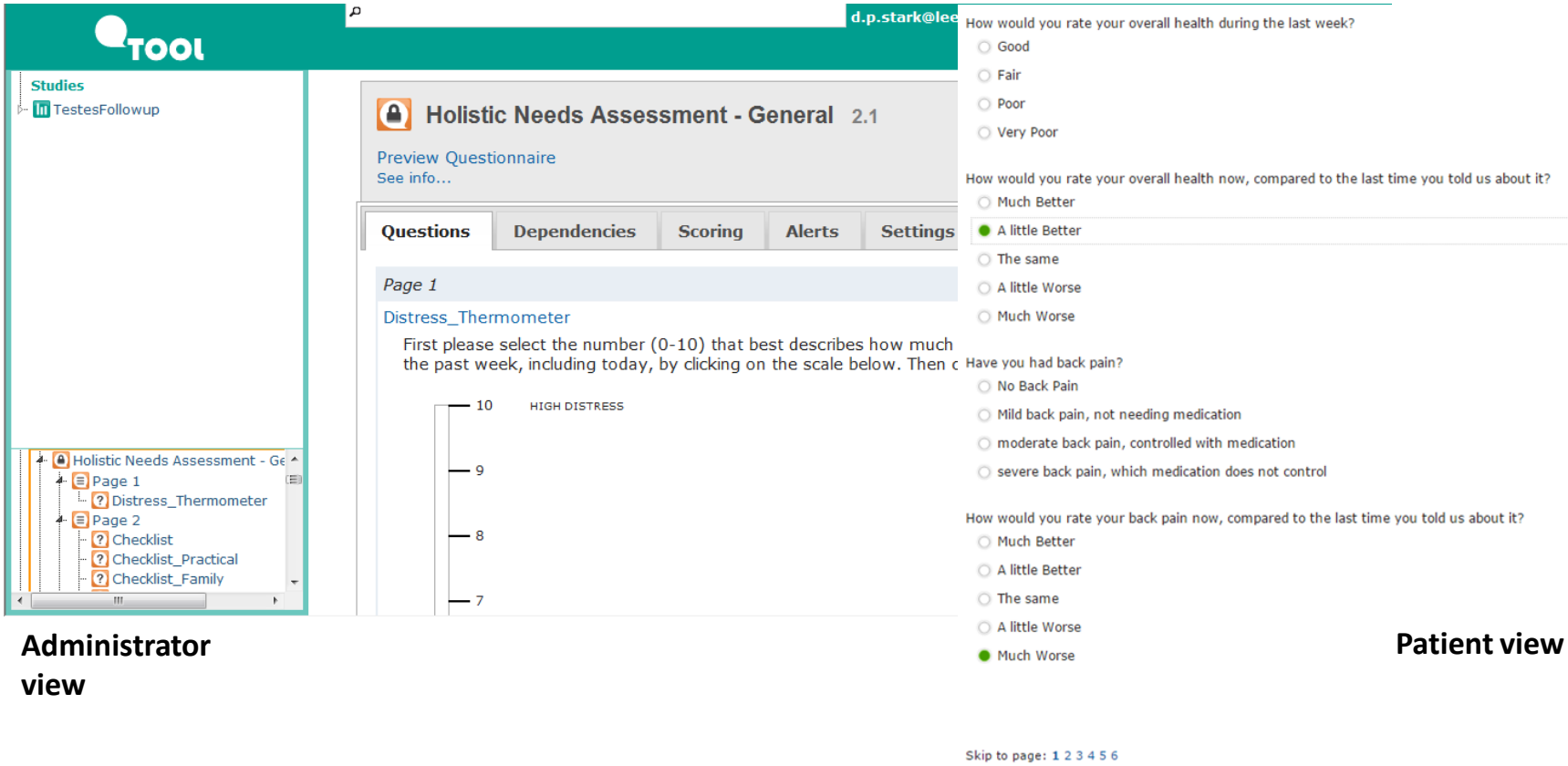
- Principles:
  - Multi-professional agreement
  - Right professional @ right time

- Tariffs for different forms of follow-up including community if delivered by LTHT, based upon multi-disciplinary workload involved
- Explicit and systematic approach
- Supported with correspondence with GP surgeries about tariffs and clinical responsibility

System requirements: Q-Tool (PCOR group)

- To replace some of the face-to-face outpatient appointments

- Germ cell tumour bespoke set of questions for patients to answer:
  - Key symptoms, self examination
  - Psychological well-being, specific concerns
  - Time and place of undertaking tests (bloods and x-rays)



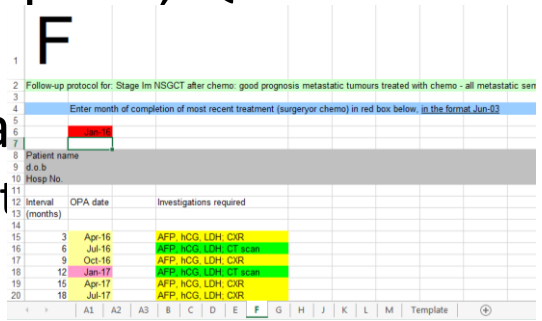
Administrator view

Patient view

System requirements: Tracker

- Relational database
- Linked to PPM1 for administrative and clinical data (+/-)
- Imports clinical data e.g. blood results, scan reports, Q-Tool responses
- Frequency and type of patient contact by trea
  - e.g. follow-up schedule F with CT at 3 and 12 mont

  from end of treatment



- Reminds clerical team by calendar of required activities
- Produces outputs – letters, (reminders, thank you, GP)

What we are doing

End of treatment:

1. Discuss options
2. Meet clerical team, check contact preferences
3. Give Q-Tool user name and password, intro to IT

Next appointment: nurse-led

1. Check understanding
2. Health promotion
3. Use of IT

Next appointments

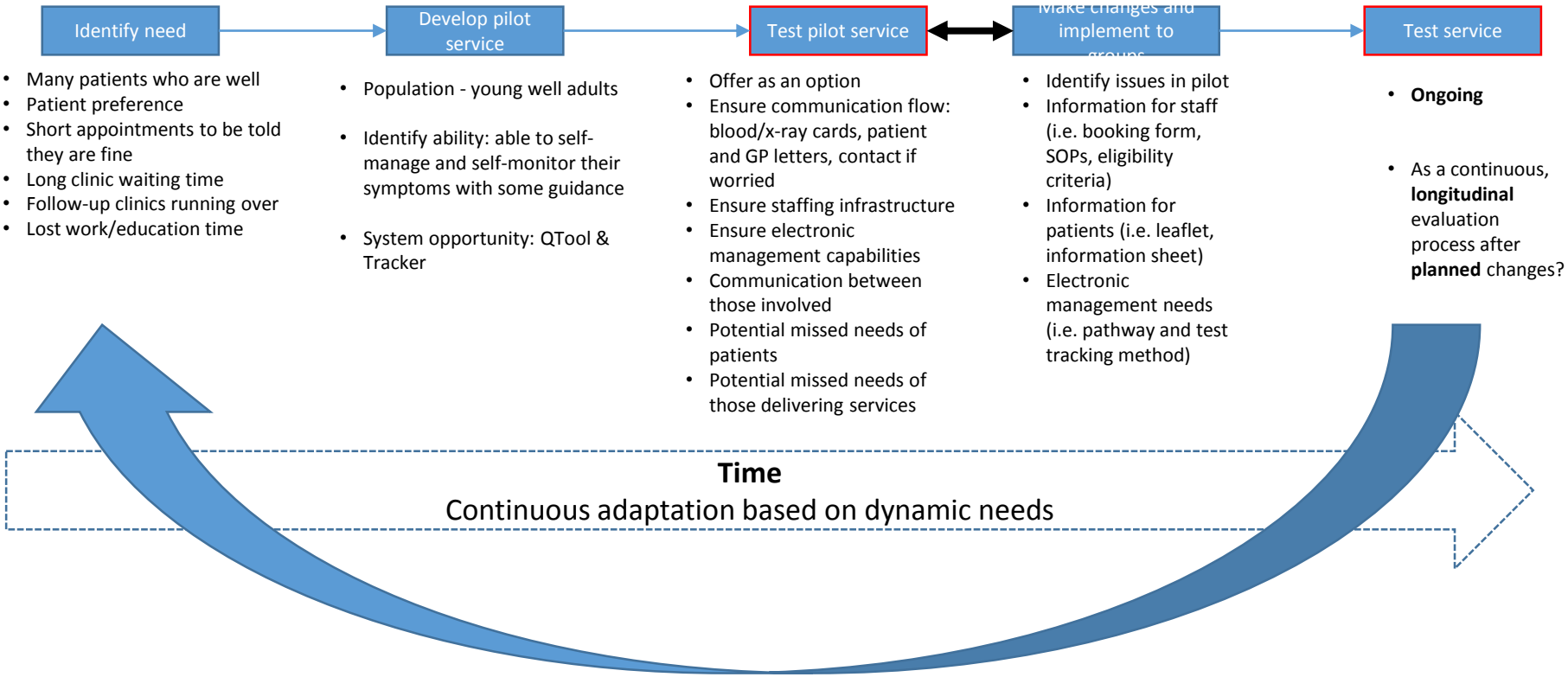
‘Community’ with minimum annual face-to-face

Clerical result collation and reminders

Clinical cross-check of collated results

Thank you letters, GP letters (populate patient record)

Implementing and Evaluating Service changes



Implementation testing - Preliminary data (work in progress)

1. Is it feasible?

A. Participation*

- Uptake (sign up, decline, switch)

B. Safety*

- Timeliness and missing data for each test

C. Service comparison*:

- DNAs & Cancellations*

D. Financial and time costs*

2. Is it acceptable?

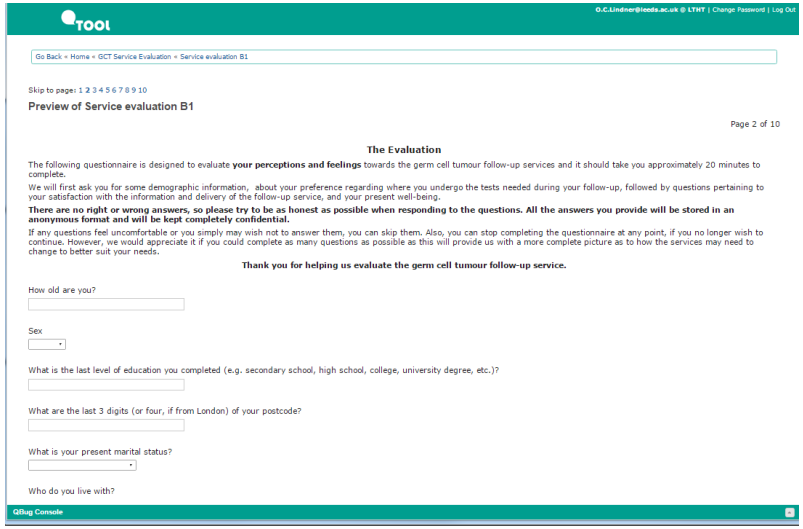
A. Information needed and provided ^*.

B. Satisfaction^*: communication, reassurance.

C. Satisfaction with software*: PPM, Tracker (staff), QTool^

D. Confidence in symptom management^*

E. Financial and time costs^*



3. Other barriers/facilitators*?

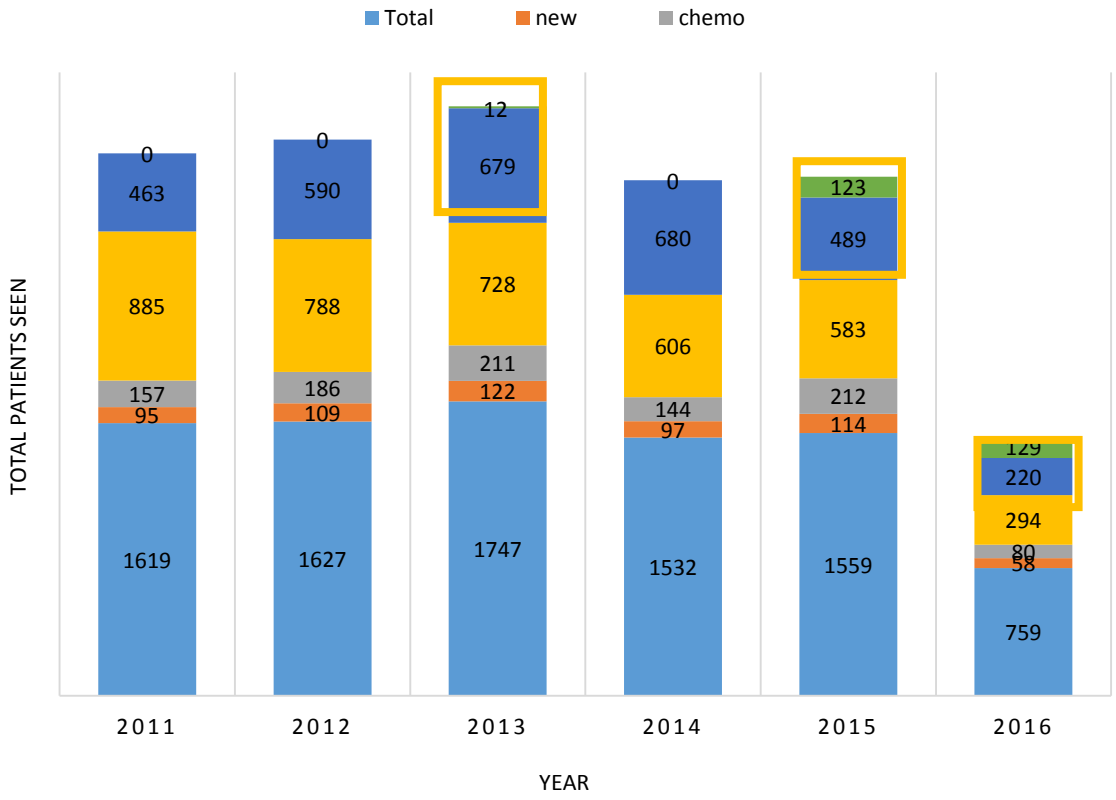
A. Patients: General health, distress, fatigue, concentration, health anxiety, cancer self-efficacy, illness perceptions

B. Staff: Job satisfaction

**Compare Community versus Standard follow-up*

^Compare staff and patient perceptions

1A. Patients under review - Service uptake (up to July)



- In service January 2016: 134 patients
- In Service July 2016: 168 patients
- November 2016: 189 patients

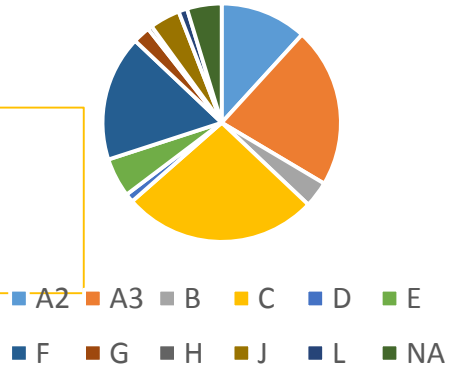
1A. Participation – Characteristics (up to July)

	2015 (12/12)	2016 (6/12)
T Patients	1559	759
N accepted CFU	123	168
N withdrawn = 18		
Reasons for withdrawal	NK Non-compliant Relapse Relocated Recruitment failure staff A/L GP issue	9 4 2 1 1 1

Factor (M/SD)	Community Follow Up (N=45)	Comments
Age	35.4 (9.42)	
Sex	F=1, M=44	
Diagnosis/treatment finished	10.05.2010-15.06.2016	
Deprivation index (IMD)	Range: 792-32027	Includes very deprived areas and substantial disability
Health and disability rank	Range: 1670-32424	

Ongoing data extraction (N=120 out of 180)

- Total in Community Follow-up (July) = 168
  - F = 4, M=164



1B. Safety

Tests		Month																Year				
J	OP/ Qtool	Last treatment	2	4	6	8	10	12	15	18	21	24	28	32	36	42	48	60	6	7	8	9	10
	Blood		2	4	6	8	10	12	15	18	21	24	28	32	36	42	48	60	6	7	8	9	10
	CXR			4		8				18				32		42	48	60	6	7	8	9	10
	CT				6			12				24			36			60					

Today

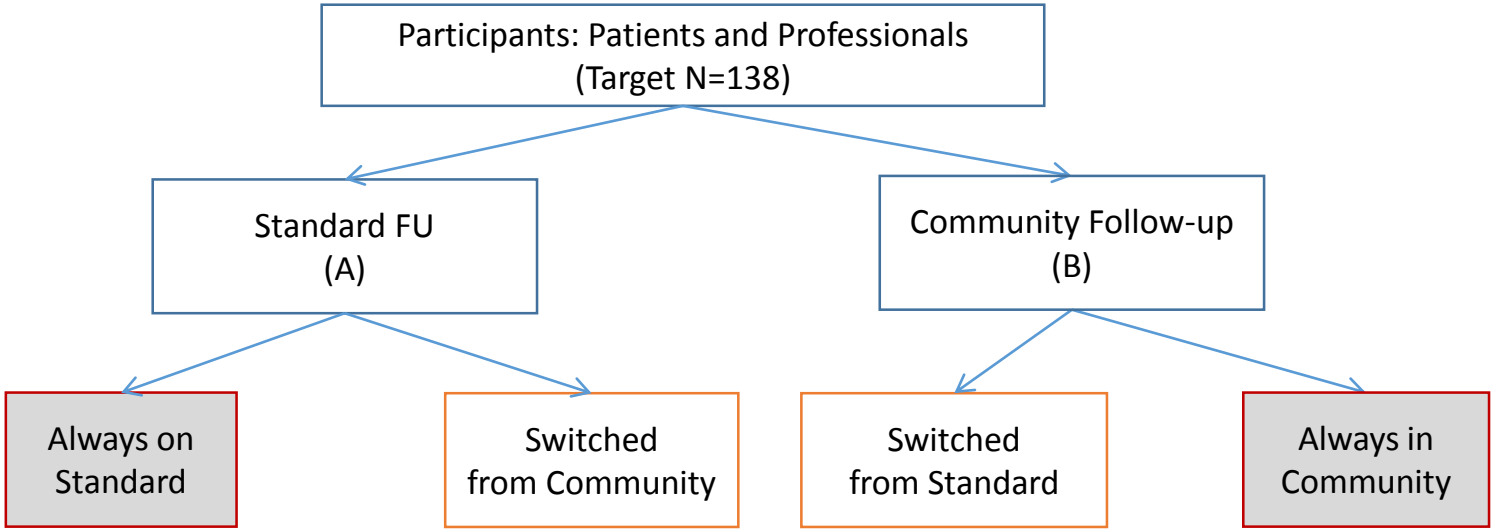
J	OP/ Qtool	Jul-14	Aug -14	X Sep- 14	Oct- 14	X Nov -14	Dec- 14	X 0	Feb- 15	X 0	✓ May- 15	✓ Jul- 15	X Oct- 15	✓ Jan- 16	Mar -16	✓ Apr- 16	Jul- 16	Nov-16	Mar -17	Jul- 17	Jan- 18	Jul- 18	Jul- 19	Jul- 20	Jul-21	Jul- 22	Jul- 23	Jul-24
	Blood	Jul-14	Aug -14	2	Oct- 14	0	Dec- 14	0	Feb- 15	0	May- 15	Jul- 15	15	Jan- 16	Mar -16	Apr- 16	Jul- 16	28	32	36	42	48	60	6	7	8	9	10
	CXR	Jul-14			Oct- 14	4			Feb- 15	8				Jan- 16					32		42	48	60	6	7	8	9	10
	CT		1				Dec- 14	6				12	✓ Aug -15				24			36			60					

Entered CFU

1D. Objective costs per patient per pathway

		A1	A2	A3	B	C	D	E	F	G	H	J	K	L	M
	OP visits/blood	12	12	15	15	26	10	17	14	23	33	21	7	7	33
	CT scans	2	4	8*	3	3	3	2	4	6	5	6	1	3	3
	CXRs	11	9	10	5	13	2	16	11	13	14	11	2	3	12
	Years	5	5	5	5	5	3	10	5	10	10	10	3	3	10
Income (first and FU attendance)	**Standard**	**1267**					**1076**		**1457**						**3647**
	Community	**1267**					**1076**		**1457**						**3647**
Expense (staff, tests, IT, Overheads)	**Standard**	**816**					**795**		**1168**						**4545**
	Community	**711**					**596**		**1047**						**4139**
Margin	**Standard**	**451**					**281**		**590**						**-899**
	Community	**556**					**480**		**410**						**-492**

2. Acceptability testing and 3. Other barriers



- Questionnaires & Interviews to collect:
  - **Recruitment : N= 64 participants since June 2016.**
  - **So far data on 45**
    - 33 wanted to be included in communications with GPs
    - Q-Tool on time in over 95% of consultations
    - Health status of patients: 82 cases good, 14 cases fair

Ongoing collection & analyses:
Information needs
Information delivered
Satisfaction with communication
Confidence in service

Ongoing Service improvements

Clearly defined eligibility criteria to the service

	Community Follow-Up Service (CFU)	
	Invite 	DO NOT Invite 
1	First year post-surgery or chemotherapy	More than 1 year post-treatment
2	Access to computer with internet	No access to computer or internet
3	Low risk of recurrence **(Paths A - F, K, L)**	High risk of recurrence **(Paths G – J, M)**
4	Able to arrange blood tests, X-rays, and complete the online questionnaire (QTool)	Not able to arrange blood tests and X-rays closer to home
5	Express a direct interest and are eligible based on criteria above	Is not able to speak/understand English without an interpreter
6		If in CFU previously, and had more than 2 DNAs for any tests → Recall for standard follow-up to re-evaluate eligibility

To be completed by Doctor or Nurse		
Insert Sticky label or **Name, DOB, and NHS#**		
Doctor arranging follow-up	Please provide initials:	Date form completed: DD/MM/YYYY
Schedule (Please circle one, from A1 to M)	A1/ A2/ A3/ B/ C/ D/ E/ F/ G/ H/ J/ K/ L/ M	Date of last treatment: MM/YYYY
Next planned appointment (for nurse-led review and discussion of community follow-up)		Please provide date for appointment: MM/YYYY Next CT Date? DD/MM/YYYY Scan requested on ICE for planned date? Y/N
Next planned face to face medical appointment (Either next CT result date or anniversary of last treatment, whichever first)		Please provide date: MM/YYYY
Service coordinator informed? Y/N		
Include in GP Letter AND patient copy (please tick if included)	**Up- to- date treatment summary with:** ☐Stage ☐Risk group ☐Pathological type ☐All treatments used ☐Month and year of last treatment	
	☐Follow-up schedule	
	Appointment schedule sheet: ☐ In notes ☐ With patient	
	☐Outline of prognosis	
	☐Comment on testicular self-examination	
To be completed by Service Coordinator		
Please tick if done:	☐Patient consented to Service ☐Patient included on PPM and Tracker ☐GP Letter sent	

Clear method to notify clinical and administrative staff involved in service

Wider adoption

- Changes made
  - Breast
  - Prostate
- In progress
  - LTFU after childhood and AYA cancer
  - Sarcoma
- Elsewhere
  - Southampton – used commercial software, so got off to a fast start - that software was withdrawn

Wider (potential) implications in cancer

Collaborative across Secondary and Primary Care

Encourage collaboration within secondary care

e.g. who delivers follow-up? surgical or non-surgical services, medical or nursing?

Risk-Stratification of follow-up

Have longitudinal PRO data

Include late effects detection and management once established