Social Integration and cancer in young people aged 16-39

Dan Stark

on behalf of

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Louise Soanes, Angharad Beckett

Summary

- Research programme which has just started - **We want to consult TYAC as the clinical experts in TYA cancer**

WHY do this research?

~300,000 AYAs (16 to 39yrs) are living with and beyond cancer. Cancer disrupts anybody's personal biography.

AYAs <u>should</u> have the same or better opportunities and socio-economic outcomes as their peers or as they would have expected if they were not diagnosed with cancer

Currently unable to undertake prospective research/trials within risk-defined groups

Aim - Define which factors (together or independently) enable or disable TYAs' **SI trajectories,** and how
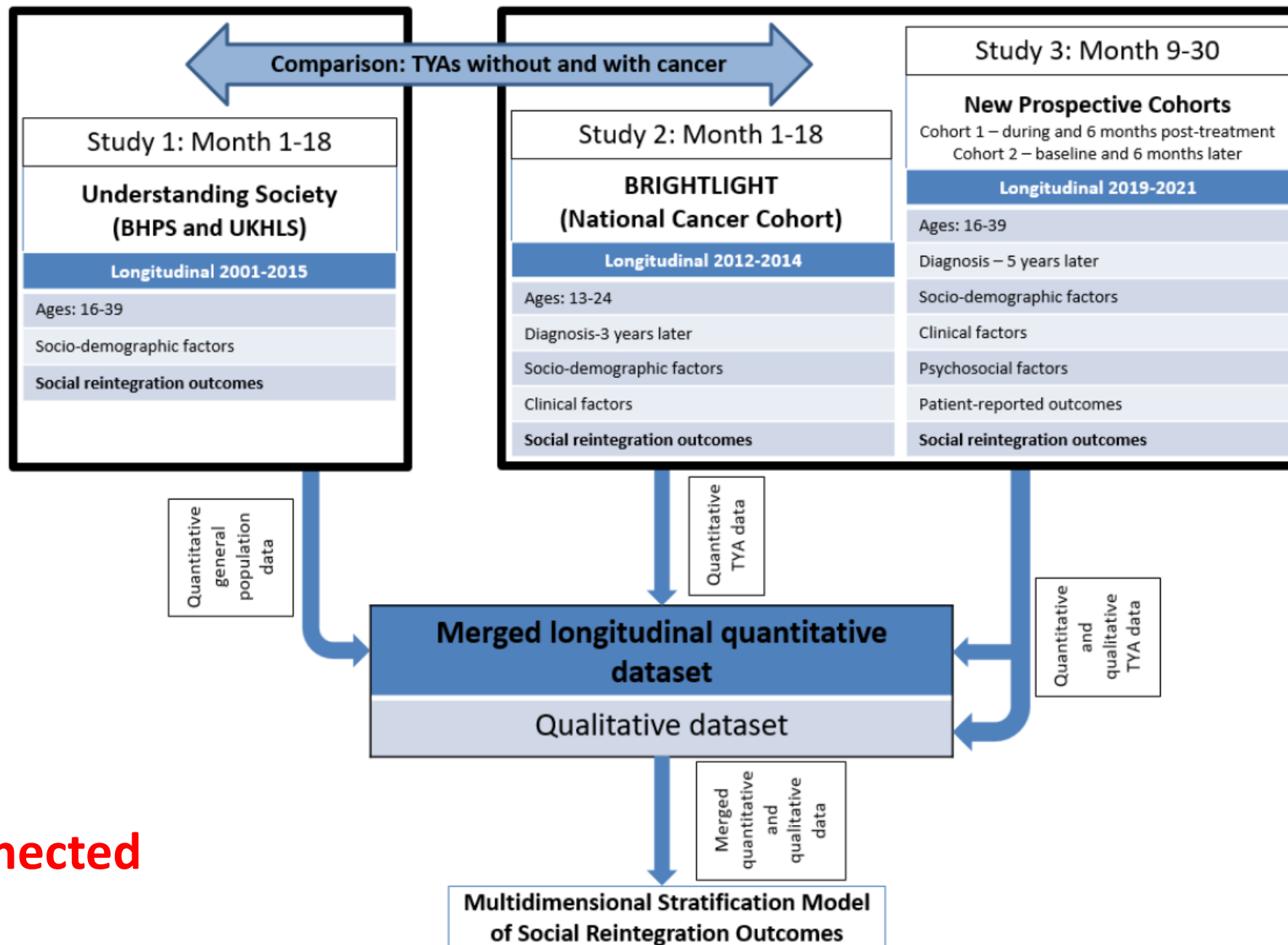
Method

- Describe SI through
  - Employment (income, type of employment, quality of employment);
  - Educational attainment (level of education and training, satisfaction, trajectory);
  - Social development (quantity and quality of social support, connections, and participation)
  - Subjective well-being.
- Link methods from oncology, psychosocial oncology, sociology, developmental psychology to inform health and social care.
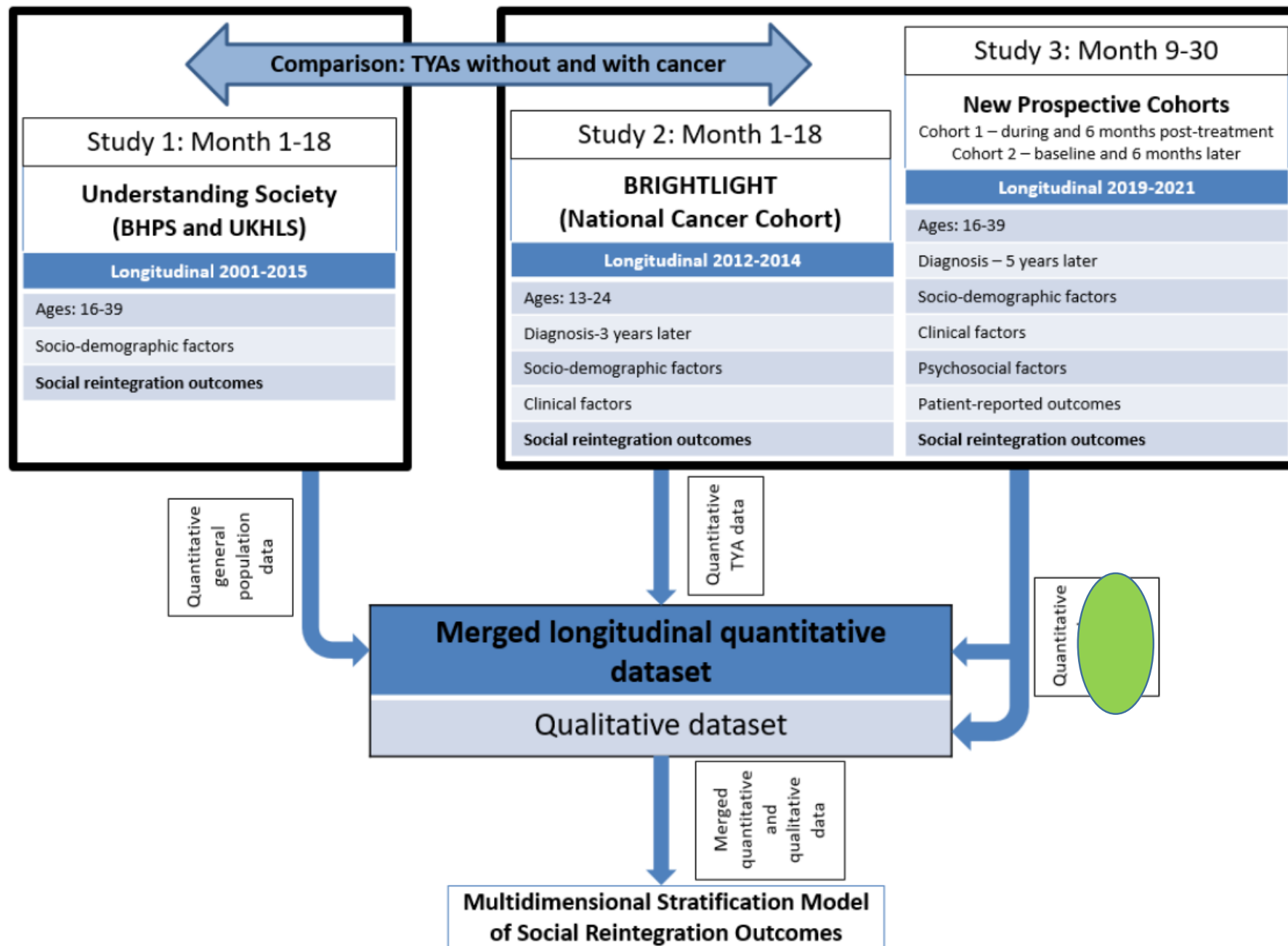
Results

A comprehensive description of the range of SI outcomes, summarised in a Multidimensional Stratification Model.

Place that within our NHS

Underpin future further intervention studies

Comparison: TYAs without and with cancer

Study 1: Month 1-18

Understanding Society (BHPS and UKHLS)

Longitudinal 2001-2015
Ages: 16-39
Socio-demographic factors
Social reintegration outcomes

Study 2: Month 1-18

BRIGHTLIGHT (National Cancer Cohort)

Longitudinal 2012-2014
Ages: 13-24
Diagnosis-3 years later
Socio-demographic factors
Clinical factors
Social reintegration outcomes

Study 3: Month 9-30

New Prospective Cohorts
Cohort 1 – during and 6 months post-treatment
Cohort 2 – baseline and 6 months later

Longitudinal 2019-2021
Ages: 16-39
Diagnosis – 5 years later
Socio-demographic factors
Clinical factors
Psychosocial factors
Patient-reported outcomes
Social reintegration outcomes

Quantitative general population data

Quantitative TYA data

Quantitative and qualitative TYA data

Merged longitudinal quantitative dataset

Qualitative dataset

Merged quantitative and qualitative data

Multidimensional Stratification Model of Social Reintegration Outcomes

Three interconnected strands

Comparison: TYAs without and with cancer

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Patient-reported outcomes
Social reintegration outcomes

Quantitative general population data

Quantitative TYA data

Quantitative

Merged longitudinal quantitative dataset

Qualitative dataset

Merged quantitative and qualitative data

Multidimensional Stratification Model of Social Reintegration Outcomes

Who?

- Principal Investigator - **Dan Stark**

- Co-Investigators
  - **Rachel Taylor** Academic Nursing, University College London Hospital
  - **Angharad Beckett** University of Leeds - Sociology & Social Policy - The politics of oppression, Citizenship and Disability, the Disabled People's Movement as a Social Movement, Anti-Ableist Pedagogy, self-advocacy and Inclusive Play.
  - **Adam Martin -** Health Economics School of Medicine Leeds - Social determinants of health inequalities, secondary analysis (observational data, real-world evidence and consumer data), data harmonisation
  - **Oana Lindner** - Psychology, University of Leeds School of Medicine
  - **Louise Soanes**, Nursing, Teenage Cancer Trust
  - **Sue Morgan,** Nursing, Leeds Teaching Hospitals NHS Trust

- New Team members
  - Research Fellows in Leeds, London
  - Data manager, Leeds

Advisory group

- **Erica Burman,** Professor of Education, Manchester
    - Critical developmental psychologist - methodologist in qualitative research
    - Connections between emotions, mental health social and individual change anchored by childhood
- **Gwyther Rees**, Research Director for Children's Worlds
    - Global study - children's views on their lives and well-being
    - Research consultant at UNICEF, in Florence – Innocenti – wellbeing & children's use of digital technologies
    - Previous Children's Society Research Director - adolescent maltreatment, disabled children
- **Helen Gravestock**, Head of Research, Policy & Campaigns, at CLIC Sargent
    - Health Behaviour Change in TYA cancer, Lifestyle after TYA cancer, JLA, Campaigns and Policy

Co-production
Of research methods
- Substantial engagement and dissemination events throughout the lifespan of this project
    - TYA Research Advisory Group (RAG) and online community
    - A community of voices from all walks of life
    - Encourage patients from each sociodemographic and clinical areas defined within this project to become involved in networks which will outlast this project

Of dissemination
- General public, patients, clinical, managerial, research professionals, policy & third sector

Study 1 - Months 1-18

- **Question -** What socio-demographic factors explain the trajectory of SI in AYAs?

Inequalities ++ in employment, educational attainment, social interactions across geographical areas - **link to medical and psychosocial outcomes** in the UK (Marmot, e.g. 2017)

Inequalities of opportunities, empowerment, and social outcomes are **likely to be increased by cancer** and its treatment

- **Aim** cohort of appropriately sampled **non-cancer TYAs to form a 'counterfactual'** for matched longitudinal comparisons

- **Design -** Extract existing data from 'Understanding Society' database

Yearly longitudinal data on the educational, employment, and social networks of people including ~54,000 aged 16-39 and about 50 with or after cancer plus more with or after other AYA illness

e.g. British Household Panel Surveys (BHPS) (1991-2008) and UK Household Longitudinal Study (UKHLS) 2008-2015

- **Analysis**

Longitudinal panel data regression models - how AYAs' SI trajectories vary by age, sex, relationship status, geographical area, and deprivation. Identify clusters

- **Limitations -** V few people reporting cancer & no clinical information for NHS application
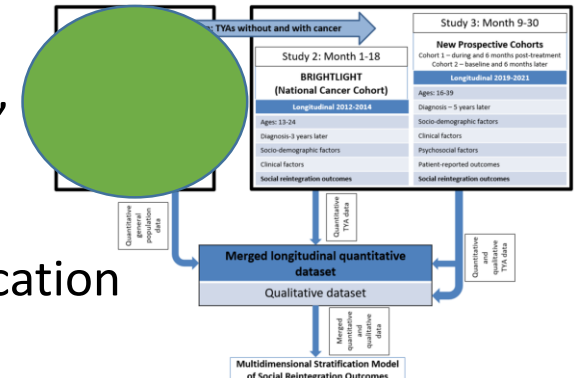
Study 2 – RQ 2 (Months 1-18)

- **Question** - What clinical factors influence SR trajectories in TYAs aged 13-24 with cancer?

- **Aim**

To compare the SI trajectory of TYAs with cancer to TYAs without cancer

Value of **clinical data (cancer type, severity, treatment)** over and above sociodemographic factors

- **Design**

BRIGHTLIGHT - 1,114 teenagers aged 13-24 diagnosed with cancer, between 2012 and 2014, from 96 NHS Trusts across England. (Taylor *et al.*, 2015) and followed up for 3 years

Includes socio-demographic, SI, clinical, and some psychosocial factors
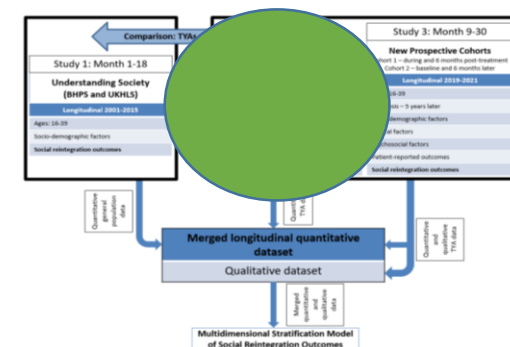
- **Analysis**

Analyse the SI trajectories of TYAs - add cancer outcomes to data also in Study 1

Identify the variability in SI within TYAs with cancer and compare to trajectories of TYAs without cancer

- **Limitations**

Not all SI and associated potential factors are recorded

The upper age limit is 24 years

Database Information	British Household Survey (BPHS) Waves 11-18	UK Household Longitudinal Study (UKHLS) Waves 1-8	BRIGHTLIGHT Survey Waves 1-5	This proposal: new prospective cohorts
Years covered	2001-2008	2008-2015	2012-2014	2018-2021
Demographic variables				
Age	•	•	•	•
Gender	•	•	•	•
Marital status	•	•	•	•
Geographical region	•	•	•	•
Deprivation index	•	•	•	•
Clinical variables				
Diagnosis	•	•	•	•
Treatment			•	•
Time since diagnosis			•	•
Time since treatment			•	•
Comorbidities	•	•	•	•
Education status				
Current educational status	•	•		•
Quality of School Life Questionnaire				•
Employment status				
Current employment status	•	•	•	•
Income	•	•	•	•
Work-Related Stress Indicator Tool				•
Social outcomes				
Household composition	•	•		•
Personal relationships: real and virtual				•
Social difficulties (SDI)				•
Patient-reported outcomes (PROs)				
Physical symptoms checklist (PedsQL)			•	•
Fatigue (Chalder Fatigue Scale)				•
Illness perception (bIPQ)			•	•
Health-related quality of life (EQ-5D)			•	•
Psychosocial factors				
Physical appearance (PedsQL)				•
Emotional distress (PedsQL)			•	•
Subjective cognitive performance (PedsQL)			•	•
Perceived social support (MSPPS)			•	•
Post-traumatic growth (PTGI)				•
Cancer and general self-efficacy (CBI and BFI)				•
Subjective well-being (SWB)				•

Table 2. Parameters evaluated in prior surveys and due to be evaluated in our proposal. Bullets depict the matching of variables across the four data sources. *Abbreviations: SDI: Social Difficulties Inventory; PedsQL: Pediatric Quality of Life Inventory, bIPQ: Brief Illness Perception Questionnaire; EQ-5D: European Quality of Life Questionnaire – 5 Dimensions; MSPPS: Multidimensional Scale of Perceived Social Support; PTGI: Post-traumatic Growth Inventory; CBI: Cancer Behaviour Inventory – Short form; BFI-10: Big Five Inventory – 10 items; SWB: Subjective Well-Being Scale.*

Study 3 – RQ3 (Months 9-30)

- **Question** - What other factors contribute to differences in SI trajectories in TYAs?

- **Design**

A prospective longitudinal **questionnaire study with a qualitative interview sub-study**, across 2 purposively sampled cohorts of TYA with or after cancer across Yorkshire and London

Quantitative - draws upon clinical epidemiology, sociology, psychosocial oncology, and developmental psychology

Considers immediate and late effects

Integrate and compare with BRIGHTLIGHT and Understanding Society.

Recruitment and follow-up - eligible people will be identified by their clinical teams aged 16 to 39, stratified by diagnosis

Cohort 1 recruited up to 10 weeks post-diagnosis

Cohort 2 recruited @ 3 to 5 years post-diagnosis

Data collected at consent and 6 months later

Over 2 years we will attempt to recruit:

- 115 with leukaemia/lymphoma, 63 germ cell, 55 central nervous system, 47 melanoma, 33 rarer cancers, 33 sarcoma patients, 21 gynaecological cancer, 19 thyroid, 11 colorectal, 4 breast cancer plus additional melanoma, breast and other cancer patients aged 25-39
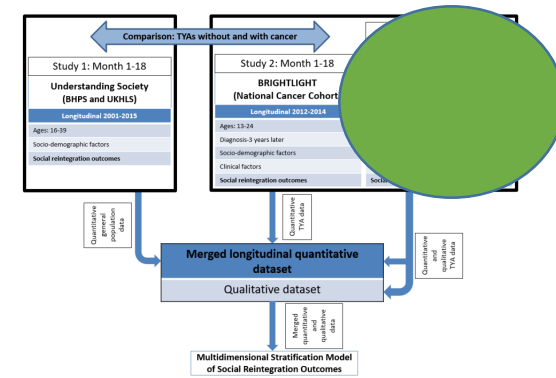
Qualitative component of Study 3

Explore patients' views of their disrupted biographies due to cancer (Bury, 1982), from diagnosis to post-treatment

- Use the cancer diagnosis as the 'critical situation' point of reference

- initial and 're-invented' biographies, ongoing or re-defined expectations, perceived factors hindering or promoting SI

- Complement and enrich the <u>causal </u>inferences

- Introduce and test newer potential factors explaining SI e.g. liminality

Semi-structured interviews with ~100 (to saturation) prospectively purposively sampled participants in the socio-demographic and clinical strata identified in Studies 1 and 2

Analyse thematically (Braun & Clarke, 2006) - inductive - patients' own interpretations and experiences emerge
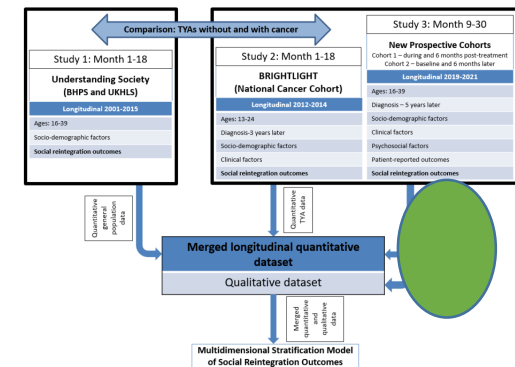
Mix the learning from Quantit. and Qualit.
- explanatory sequential design (Creswell,2015).

- Quantitative data first
- Then qualitative then
- Back again

In the figure:

- Time/Lifespan
  - Diagnosis and treatment
  - End of **curative** treatment
  - End of **active** monitoring
  - **Active treatment**
  - **Survivorship: Active surveillance**
  - Long-term monitoring

- Age, Gender, Education, Deprivation area, Geographic area — **Socio-demographic factors**

- Diagnosis, Treatment, Time since diagnosis/treatment, Co-morbidities — **Clinical factors**

COVARIATES

Patient-reported outcomes (PROs)
Ongoing symptoms
Fatigue
Illness perceptions
Emotional distress
Physical appearance
Cognitive difficulties
Health-related quality of life (QoL)

Psychosocial factors
Social difficulties
Perceived social support
Personal psychological development (i.e. extraversion/post-traumatic growth)

Emergent factors

Social Reintegration Outcomes (SROs)
Educational attainment: Current status & satisfaction
Employment attainment: Current status, income & satisfaction
Social development: Quantity and quality of social support
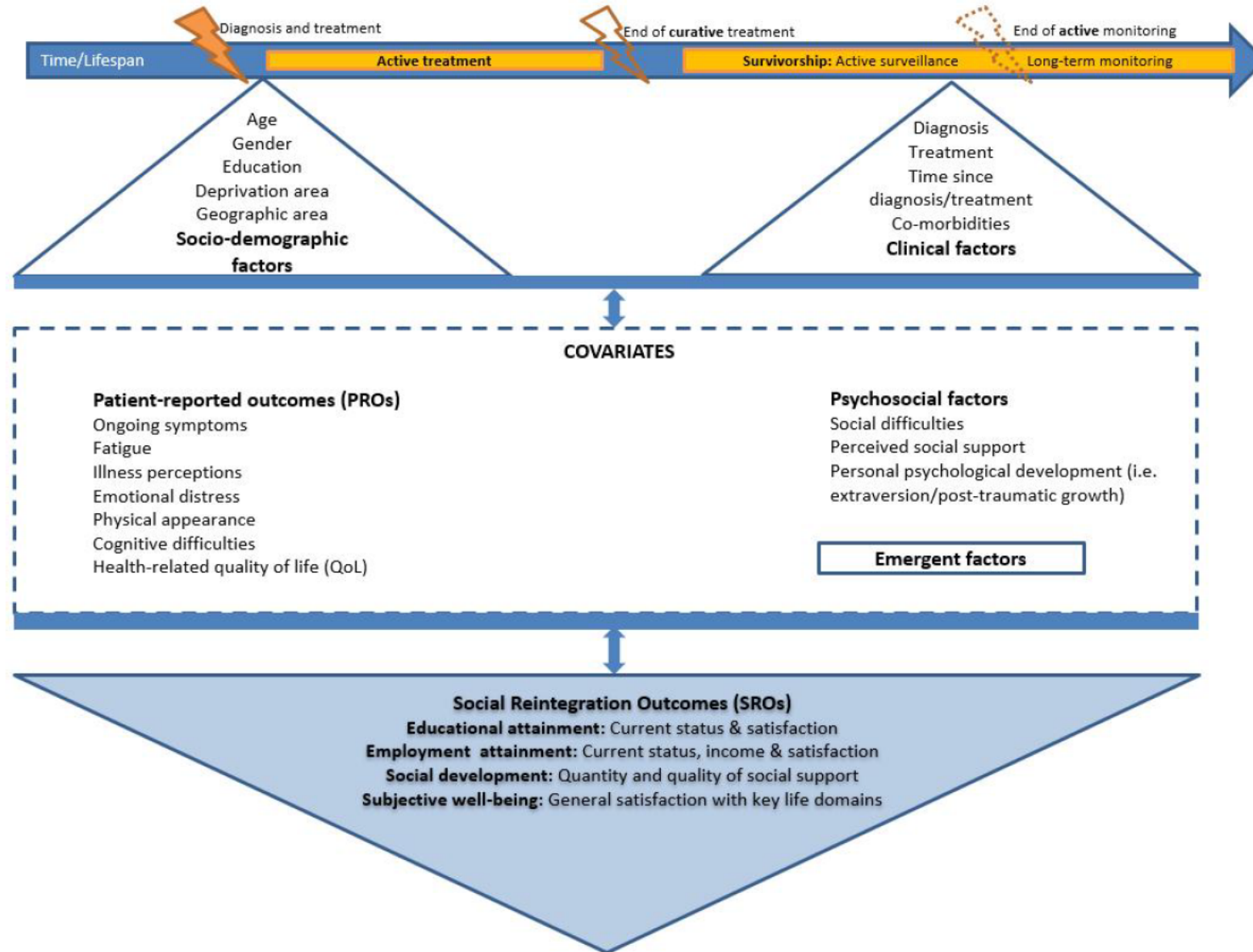**Subjective well-being:** General satisfaction with key life domains

Figure 1. Graphical depiction of the proposal and its output. Socio-demographic, clinical, psychosocial factors, and patient-reported outcomes to be measured, hypothesised to explain variation in the Social Reintegration Outcomes (SROs) and trajectories in young people during and after a cancer diagnosis. We will allow for the emergence of new potential factors describing SROs through the qualitative component of the study.

Study 4 - Integration within existing clinical, social and psychological NHS policy & practice
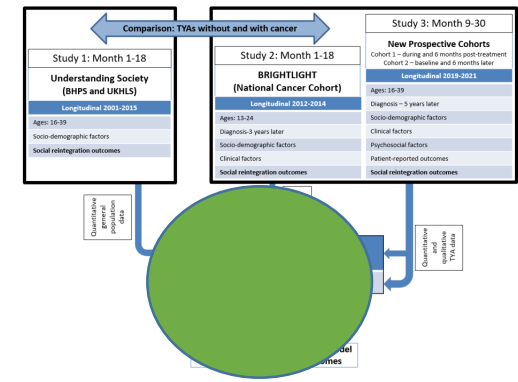
Question - How to integrate our 3 studies within a Multidimensional Stratification Model of Social Integration Outcomes into the NHS,

- reduce inequalities

Method Co-Production - patients and healthcare professionals co-deliver

- Strategies: educational and experience-sharing videos, public health information, e-learning modules, meetings, online discussions.

- C.f. other successful initiatives - ImproveCareNow network (Batalden *et al.*, 2016) - The Health Foundation's Co-Creating Health Initiative (Barnard *et al.*, 2009).

- Patient & professional learning networks - 'what-matters-to-you medicine' (Barry & Edgman-Levitan, 2012)

- Final dissemination workshops delivered by patient representative and healthcare professional or researcher with co-designed resources, to share patient and professional perspectives and future project plans for pragmatic cancer-related health and social service development

Outcome

- Policy proposals to implement 'all of our' model within NHS cancer services

Thank You

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Questions - now or later?