

What: We designed and hosted a patient, public and professional engagement and dissemination event centred upon the 'Impact of cancer diagnosis on social reintegration' ESRC research Programme (Grant ES/S00565X/1)



The event had as its by-line 'When you know or you meet a young person living with or after cancer or another illness, what simple things can you do to support them?'

The event was led by Professor Stark, working in particular with:

- Clinicians in Leeds' NHS Cancer Services
- Charities: Local (Yorkshire and the North East) staff of the Teenage Cancer Trust (who contributed some funds as well as engagement) and Young Lives Vs Cancer charities respectively
- Young people living with and after cancer in Leeds and elsewhere
- Angharad Beckett and colleagues from Social Sciences, Uni Leeds
- Oana Lindner a post-doc in Leeds Institute of Medical Research
- Adam Martin from Leeds Institute of Health Sciences, Uni Leeds
- Alice O'Grady and colleagues from School of Performance, Uni Leeds
- The Festival organisers, notably Cheryl Harris, Celine Roblin-Robson and the Uni Leeds Internal Comms team
- The recently founded CHORAL collaboration within University of Leeds

The content included:

1. Testimony from a senior healthcare professional (Lead nurse for TYA cancer services, Leeds) about their experiences of social integration after cancer. We planned testimony from a young person undergoing cancer treatment and their partner?, but they were unable to contribute at short notice due to issues beyond their control. Now, we plan to record a conversation with them to provide through our web page for the Patient-Centred Outcomes Research group <https://pcor.org.uk/tya/>.
2. Outline results from the project to date.
3. Break-out groups online and in person to enable a wider range of more detailed personal experiences and perspectives.
4. Quotes from young people who took part in the research

'What is normality?'

'So I mean, some of that pressure came from me...I just want to get back to normal as quickly as possible. And I kind of really pushed myself into it...a little bit too hard ... not realizing the long term impact (F, 25+, Lymphoma, London)

Friends (understanding)'

‘one of my closest, closest friends, my best friend in the world (...) there was a massive disconnect because I think she came to she came to visit me once and I think she wasn't quite expecting the gravity of it all. (F, 16, Lymphoma, Leeds).’

5. Videos previously produced in collaboration with the TYA research and clinical teams. These short vignettes were parts of existing drama performances developed in University of Leeds, through international collaborative research between the School of Performance and Cultural Industries at the University of Leeds and Royal Roads University in Canada. Young people locally and internationally translated their experience into a creative format. They used dramatic performance to express and understand their reveal the unique insights into how it feels to be a young person with cancer experiences. Short performance videos were crafted in 2021 by young people who have undergone cancer treatment, to illustrate their experiences of cancer. Excerpts were selected to highlight social issues within the impacts of living with and after cancer.
6. We shared the content generated in the breakout groups, sources of existing information about support for TYA living with and after cancer, and next steps
7. We shared existing resources created to help all stakeholders manage these pressures

Who: We shared the opportunity in advance, through networks of our own, wider University of Leeds academic and public engagement networks, the engagement networks of the Festival of Social Sciences, local and national charities for young people with illness, local employers and educational provider networks.

We sought to, and succeeded in engaging:

- Young people aged 15-39 living with and after cancer or another illness
- The loved ones and carers of young people living with and after cancer
- Young people who don't have an illness, but would like to find out more about how to support young people they know if and when they are ill.
- Employers who wish to help young people to work with them during or after illness
- Schools, colleges and universities who wish to help young people to study and learn with them during or after illness.
- Community-based organisations (such as charities, societies and informal groups) that wish to help further.

To achieve this:

- We prepared, created and shared brief content to engage them with the event, and fuller information resources to explain in further detail for those wishing that, adapted to the perspectives of different participants.
- We engaged 10 facilitators, from healthcare professional and academic backgrounds, to support the successful running of the event and breakout groups both online and in-person.
- We engaged enhanced information technology support to facilitate the successful event experience, online in particular, as the University of Leeds support available was not sufficient.

Where: Parkinson Building, University of Leeds, as part of the ESRC Festival of Social Sciences



How: Hybrid – the meeting was held simultaneously in person and online on Zoom. We provided the same content and agenda in both. An illustrator in the room created visual materials in real time about what they heard said and the issues that raises.

When: Wednesday 8th November 2023, 1730 to 1930

Why:

Primarily: We wanted the public to help to make the lives better, of young people living with and after cancer. Young people get cancer. Thankfully most survive nowadays. But the consequences for their future lives are often huge. There are relatively simple things the general public, employers, educators and our community organisations can improve, to better support these young people when they are living with or after cancer. We wished to share our recent large-scale research about what these are.

Secondarily: We are well advanced in our analyses of the research programme data for the 'Impact of cancer diagnosis on social reintegration' project. Having consulted with and implemented that project with TYA and health care professionals, we have conducted detailed analyses for study 1 'Social trajectories in the well population and those with non-cancer illnesses', and study 2 (comparing cancer to the well population 2014-2017), initial framework analyses of qualitative data in study 3 (cancer social outcomes 2019-23), are preparing for detailed quantitative analyses for study 3 and the final shape and form of study 4 (a multidimensional risk stratification for AYA with cancer). We wished to triangulate our current observations with the lived experiences of experts and use that to better plan our next analyses. We undertook to the funder in our project to plan substantial engagement and dissemination events throughout the lifespan of this project, directed at the general public, patients, clinical, managerial, and academic professionals, and third sector stakeholders.

Thirdly: this event enabled further engagement across the range of current and potential future collaborators in this field, to strengthen our work in dissemination, policy and future research.

We aimed to give attendees

- A greater confidence in dealing with this situation when it arises, as it does for us all.
- A wish to be able to give back constructively to members of their community who can feel and be socially excluded.
- A wish to help their organisation be more constructive for young people who are, or have been, unwell.

Findings:

The event was accessed by 40 people during it, 14 in person and the remainder online. Of those 6 were healthcare service users, 7 were educators, 6 were from community organisations and 21 were healthcare professionals. We did not attract any attendees from employers organisations.

Before the event there were 19 engagements and 1201 impressions on X/Twitter. During the event there were 63 engagements and 528 impressions.

Our recent research on many thousands of adolescents and young adults in Leeds, London and elsewhere in the UK aged 15-39 showed that a number of the challenges young people face with and after cancer (and other illnesses) are 'social'. That means the young people find returning to mixing with people who don't have cancer is difficult. This might be in their social lives but also in employment, education or even their family.

What we have also identified is that simple awareness and minor actions may reduce this problem. What these young people need is not particularly complicated or clever – a few simple things anyone or any organisation can do could really help. I wanted to share this learning with the community in Leeds, hear their experiences and use their experience as part of how we use this research to make a difference.

During the event:

The rationale for the study was well accepted as critically important to young people. The comparative nature of the study, to those with other illnesses and no known illnesses was important, but nuanced because of the range of chronicity of different illnesses. Cancer tends, with some exceptions, to be a relatively brief episode of severe illness, with either recovery or death. Several other young-onset illnesses are chronic and do not resolve in this manner. Some are episodic, as cancer can also be.

We noted, after young-onset illness;

- Delays and non-completion of educational achievements when living with illness. These vary substantially by gender and illness type, so seem likely to be tractable for improvement.
- More young people after cancer (than in the general population) embracing further and higher education after they complete cancer treatment. Those not in education, employment or workplace training with cancer are 8 times more likely to enter education than non-illness comparators. Most were exiting progressively (i.e. into a higher level of education not to re-take previous education missed)
- Less employment and income in those living with many (but not all) illnesses, especially in women, and some of it persisting until the age of 40 at least.
- Fewer with illness are living with their parents, although more moving back into the parental home
- Variation by illness group in the proportion entering a long-term relationship, which varies by gender. More relationship breakdown (2.3 fold increase) after cancer in particular, compared to the non-illness population comparators.
- A huge increase in the prevalence of mental health problems, at clinical disorder level, comparing young people living after cancer in 2014-2017 to 2019-2022.
- Friendship problems may be underpinned often by a lack of continuing shared perspectives and understanding.

Discussions in large and small groups yielded *key further observations*:

Huge current levels of financial challenge, with some counterbalancing supports (but not equitably available)

We need to conduct analyses that detect and value our data heterogeneity:

- The age ranges included and not treat these as homogeneous.
- Impact of race and socio-economic group on social parameters
- Length of stays in hospital may relate to social challenges

Support available to young people with cancer is not equal, in particularly in disadvantaging those aged 25+

To understand the factors which may predict adverse or positive social outcomes:

- When does illness strain a relationship and when does it bring them together?
 - Illness as a positive – such as overcoming social anxiety
 - How much does Fertility (or fears about it) impact social engagement?
- How strong is the relation of Mental Health to social wellbeing, especially for those influenced by intersectionality:
- o Services are not delivering on existing MH promises through formal systems. Are other initiatives, through drama or other approaches, realistic and effective?
 - o General MH services in our communities are not well suited to manage MH problems in serious physical illness.

There are gendered issues prominent in these findings. These sit counter to clinical experience of better care engagement in females, so imply intersectional problems or bigger societal issues

Hard to pre-empt problems accurately in clinical experience, although structured assessments exist.

Tailored education support might extend from schooling and university to adult learning programmes

The plasticity of the developing brain may be relevant to integration. This might be studied in future, in psychological and physiological research designs

Young people may benefit from preparing for transitions in treatment earlier, guided and steered by health services, to prepare them for social integration. It may also help to soften the end of treatment as a precise point in time, with courses preparing for that which start earlier.

Comparison is a natural element of being a young person, but not constructive, and particularly promoted by much social media discourse.

Employers are pressurising young people in relation to their performance at work, while not understanding the lived experience of the patient. This may need review of the guidelines and legal requirements upon employers, and if that is insufficient, then national recognition

Young people find it hard to ask for support in social issues – reaching out may feel intrusive upon the care available to others. It may be better to plan these discussions routinely, to identify risk and intervene early, not only deliver them in reaction, when help is sought because a problem has occurred and become major enough for someone to ask for help.

- Awareness of cancer (seemed higher in universities than colleges/schools, but not systematically measured)
- Young people identified the critical role of NHS staff (Often actually charity-funded) to help navigate the bureaucracy of education when unwell
- Young people very often re-evaluate their educational and life goals when living with illness. Some choose to change education pathway– this needs to be normalised for patients, carers and organisations, as it is not constructive to frame changing subject or aims as a sign of failure.
- Everyone should allow people living after cancer to determine whether and when they talk about it.
- Remember it is not always known how long successfully treating an illness will take.

Young people living with or after illness need to be offered additional support, in education, places of work, friends and families.

- Young people feel an internal 'pressure' to return to 'how they were before' and this pressure over time many reflect did not help them socially re-integrate.
- But not be expected to 'take it or leave it' – leave the offer open until people have processed information and are ready to anticipate and act upon the social challenges ahead of them.

Clear concise information about workplace and educational policies, expectations, rights and routes to support are helpful.

- Good record-keeping enable promises to be kept if managers change roles.
- Preparation, understanding and awareness in staff, encouragement to disclose about the illness in managed stages (with colleagues, managers, educators, peers and others).

Young people may benefit from mental health support from youth workers and others within health services, even if they seem OK, to give them practical tips and skills to return to their social environment. Structured mental and social health interventions may be required for all and starting from the point of diagnosis, in preparation for social re-integration with or after illness. These may include help to leave home again, and introducing more flexibility into the natural young persons' feeling of comparison, and of hurry to 'get back on track'.

It may also help to soften the end of treatment as a precise point in time, with courses preparing for that which start earlier.

Next steps

Multivariable analyses of key associations, and further triangulation between the quantitative and qualitative data based upon the key observations in this event

The fuller videos of experiences should be made available more widely online, within any participant and/or funder restrictions

Press-Media activity

Further similar re-engagements, at key future points such as Pint of Science May 2024

Engagements to further promote diversity

Engagements with policy-makers as data becomes available of relevance to them

Exploratory further focussed engagements with local employers- what will work for them?

- Self-employment is particularly challenging in older AYA

Specific further engagements with educational organisations, where we have identified specific further areas of work. There seems to be very beneficial work to be done on educational re-engagement after a health shock, and a beneficial message to educational providers, that there is a great deal of good they can do in this group.