

Hands On, Mixed Methods Research with Public Patient Involvement

by Cathy Street and Suzanne Gerritsen
Winter Conference, Belfast,
November 14th 2019

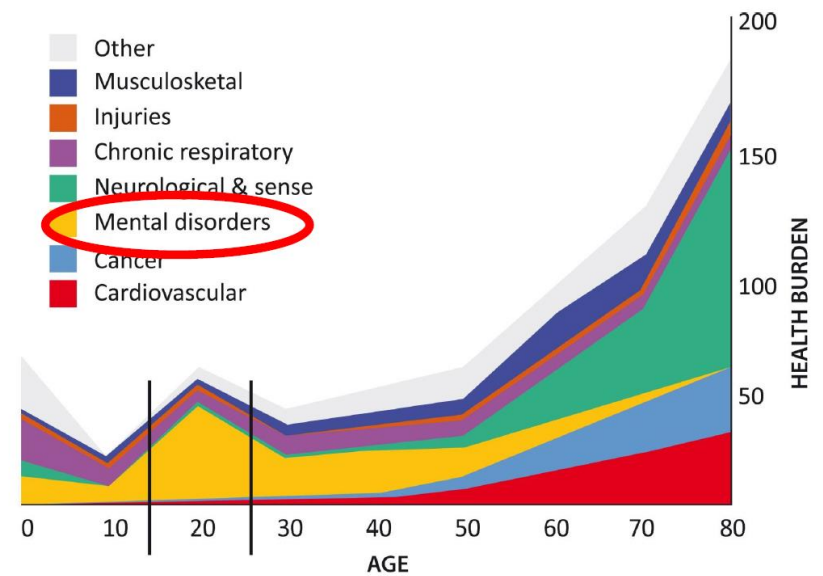
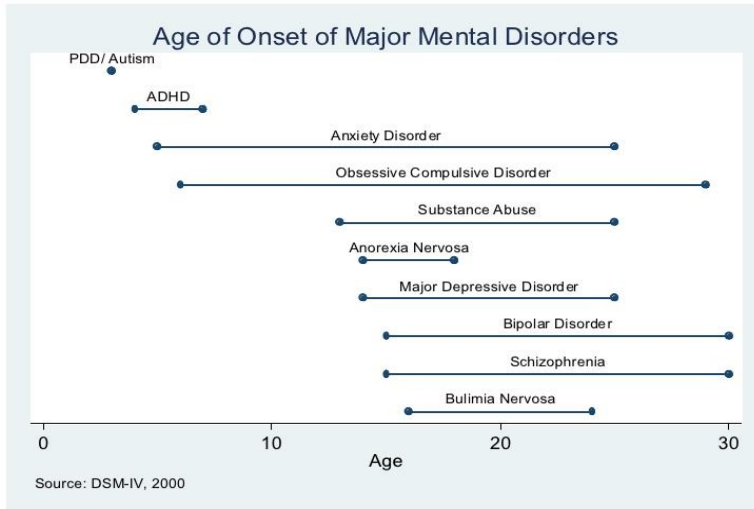


Transition

“Transition is a planned and purposeful **process** that addresses the psychosocial and medical needs of adolescents and young adults with chronic physical and medical conditions as they move from child-oriented to adult oriented health-care services” (Department of Health, 2006)

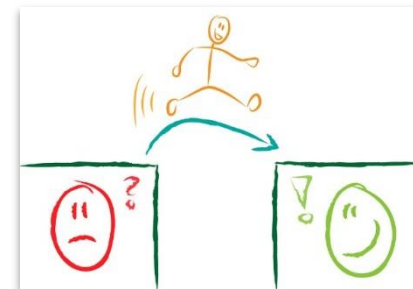


Peak in onset & burden of mental disorders at adolescence/young adulthood



Research on transition

- Young people, parent/carers AND clinicians have bad experiences with transition from CAMHS to AMHS (Hovish, 2012; Paul et al., 2013; Paul et al., 2014)
- Only few YP with a need for care get (the appropriate) mental health care, which affects long-term mental health outcomes (Offord et al., 1989; Kataoka et al., 2002; Davis, 2003; Giralomo, 2012)
- Swaran Singh (2009) concluded: “Current service configuration of distinct Child and Adolescent Mental Health (CAMHS) and Adult Mental Health (AMHS) Services is considered the weakest link where the care pathway should be most robust.”



Research on transition

- Recently more studies have investigated transition trajectories in relation to mental health: Leavey et al. (2019), Perera et al. (2017) and McNicholas et al. (2015)
 - One in four young people transition from CAMHS to AMHS
 - A similar proportion stays in CAMHS
 - Estimates of discontinued care despite ongoing needs: 30 – 84%
 - Predictors of transition have been identified (male gender, more internalizing problems, severe and enduring mental illnesses, not being in education or employment, psychotropic medication prescribed etc.)

***In Ireland, we know that transition is a problem :
young people often end up having to pay for private help due to lack of AMHS***

Research on transition in Ireland

Early Intervention
IN PSYCHIATRY

First Impact Factor released in June 2010
and now listed in MEDLINE!



Early Intervention in Psychiatry 2014; 8: 291–297

doi:10.1111/eip.12073

Early Intervention in the Real World

Transition from child and adolescent to adult mental health services in the Republic of Ireland: an investigation of process and operational practice

Niamh McNamara,¹ Fiona McNicholas,^{1,3} Tamsin Ford,⁹ Moli Paul,¹⁰ Blanaid Gavin,³ Imelda Coyne,⁴
Walter Cullen,⁵ Karen O'Connor,⁶ Nicolas Ramperti,⁷ Barbara Dooley,² Siobhan Barry⁸ and
Swaran P. Singh¹⁰

Who is in the transition gap? Transition from CAMHS to AMHS in the Republic of Ireland

F. McNicholas^{1,2,3,*}, M. Adamson¹, N. McNamara⁴, B. Gavin², M. Paul⁵, T. Ford⁶, S. Barry⁷, B. Dooley¹, I. Coyne⁸, W. Cullen⁹ and S. P. Singh⁴

¹ Department of Child Psychiatry, University College Dublin, Dublin, Ireland

² Lucena Clinic, Dublin, Ireland

³ Our Lady's Hospital for Sick Children, Crumlin, Ireland

⁴ University of Bedfordshire, Leeds, UK

⁵ University of Warwick, Warwick, UK

⁶ University of Exeter Medical School, Exeter, UK

⁷ Cluain Mhuire Adult Mental Health Service, Dublin, Ireland

⁸ Trinity College Dublin, Dublin, Ireland

⁹ Department of General Practice, University of Limerick, Ireland

Objective. The ITRACK study explored the process and predictors of transition between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) in the Republic of Ireland.

Attaining the age threshold for adolescent mental health services: factors associated with transition of care in the independent sector in Ireland

L. Bond^{1,*}, A. Feeney¹, R. Collins², I. Khurshid¹, S. Healy¹, A. Murtagh¹ and P. Power^{1,3}

¹ Department of Psychiatry, St. Patrick's Mental Health Services, Dublin, Ireland

² Primary Care Psychology, HSE Community Health East, Dun Laoghaire, Dublin, Ireland

³ Department of Psychiatry, Trinity College Dublin, Ireland

Objectives. The transition from adolescent to adult mental health services (AMHS) is associated with disengagement, poor continuity of care and patient dissatisfaction. The aim of this retrospective and descriptive study was to describe the 'care pathways' in an independent mental health service when adolescents reach age 18 and to investigate the level of engagement of those who transitioned to independent AMHS.

Reasons for further research

- **What happens to young people** who transition / do not transition to AMHS?
- What are the **ethical or legal aspects** of transitional care?
- **Lack of adequately powered studies** (RCTs) evaluating the effectiveness of transitional mental health care models
- What is the real **cost of transition**?
- Little or no work with a **pan-European focus**
- **Need for high quality research**, informed by and involving young people who have experienced transition from CAMHS and research in different countries





Evaluating an innovative transitional care model.

FACTS & FIGURES



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442



Full project title:	THE MILESTONE PROJECT: Managing the Link and Strengthening Transition from Child to Adult Mental Health Care
Start date:	1 st February 2014
Duration:	5 years
Project coordinator:	University of Warwick, Prof. Swaran Singh (MBBS, MD, DM, FRCPsych)

AIM:

To understand and improve transition of care from Child (CAMHS) to Adult mental health services (AMHS) across different healthcare systems in Europe



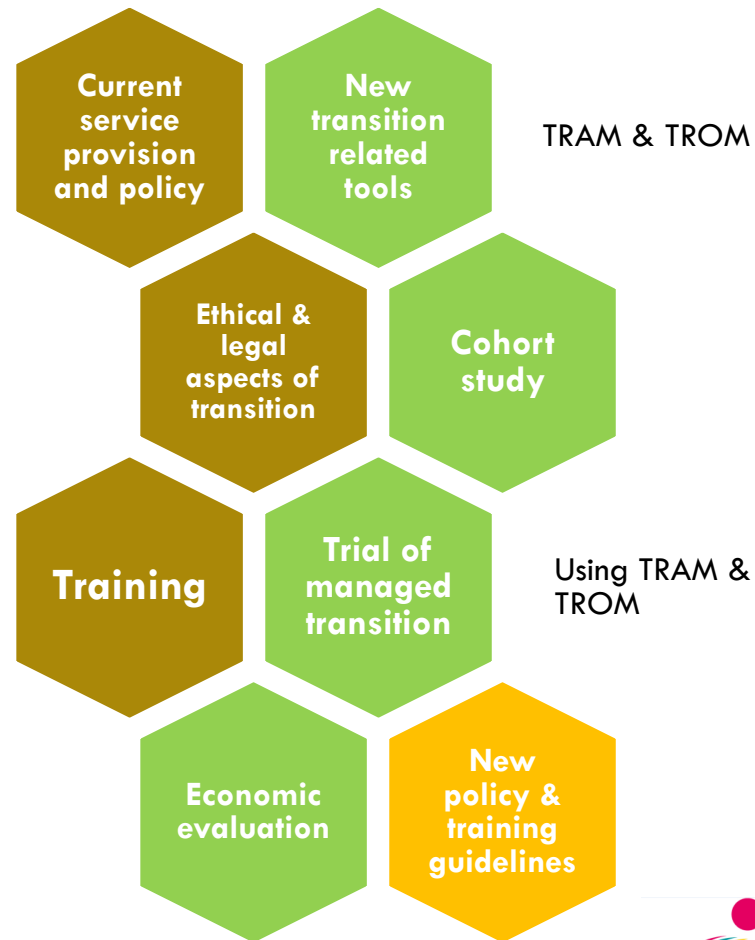
- [PROJECT COORDINATOR AND PROJECT MANAGEMENT OFFICE](#) →
- [MEMBERS](#) →
- [SCIENTIFIC CLINICAL AND ETHICAL ADVISORY BOARD \(SCEAB\)](#) →
- [PROJECT SUMMARY](#) →
- [FACTS & FIGURES](#) →

MILESTONE partners

The map displays the following partner locations and logos:

- Dublin | Ireland:** UCD DUBLIN logo.
- London | United Kingdom:** KING'S College LONDON logo.
- Caterham | United Kingdom:** HealthTracker logo.
- Warwick | United Kingdom:** WARWICK MEDICAL SCHOOL logo.
- Rotterdam | Netherlands:** Erasmus MC logo.
- Dordrecht | Netherlands:** Erasmus MC logo.
- Leuven | Belgium:** KU LEUVEN logo.
- Ulm | Germany:** Yulius logo (VOOR GEESTELIJKE GEZONDHEID).
- Fürstenfeldbruck | Germany:** Yulius logo.
- Brescia | Italy:** Kinder- und Jugendpsychiatrie / Psychotherapie logo (Universitätsklinikum Ulm).
- Split | Croatia:** UNIVERSITY OF SPLIT logo.
- Montpellier | France:** CHRU MONTPELLIER logo (CENTRE HOSPITALIER REGIONAL UNIVERSITAIRE).
- Provincia Lombardo-Veneta:** Ordine Ospedaliero di S. Giovanni di Dio - Fatebenefratelli "CENTRO S. GIOVANNI DI DIO - FATEBENEFRAELLI" ISTITUTO DI RICOVERO E CURA A CARATTERE SCIENTIFICO (D.L. 19 dicembre 1996).
- concentris research management** logo.

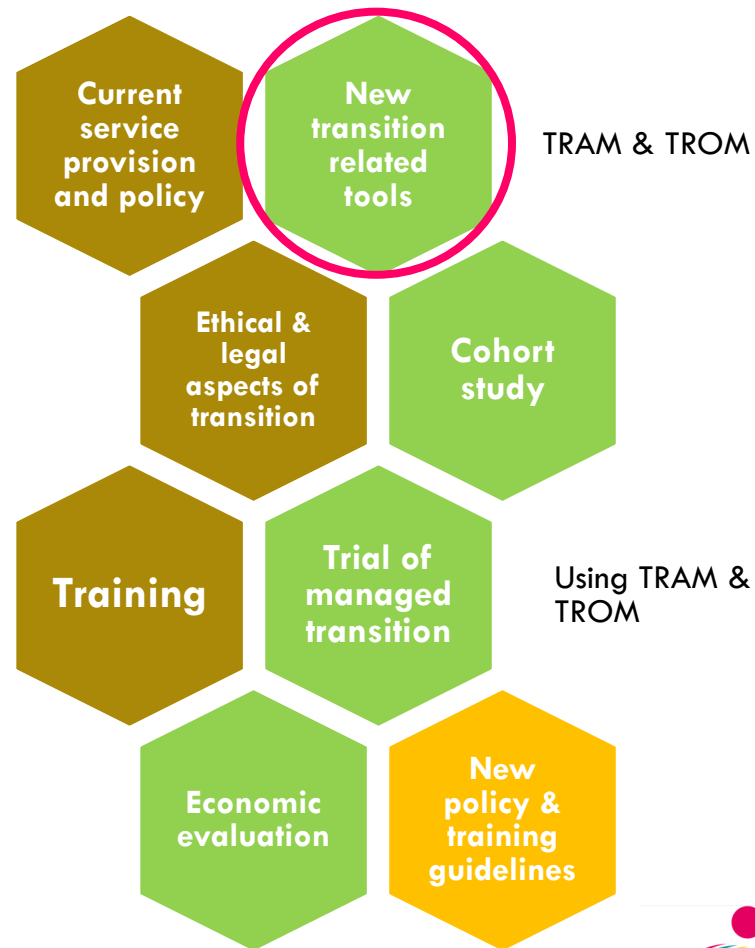
Themes covered by MILESTONE



TRAM = Transition Readiness and Appropriateness Measure
TROM = Transition Related Outcome Measure



Themes covered by MILESTONE



TRAM = Transition Readiness and Appropriateness Measure
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Development of TRAM

- Transition Readiness and Appropriateness Measure

Readiness to transition =
Functioning

- Potential barriers & changes in YPs life

Appropriateness to transition =
Need for ongoing care

- Frequency & severity of symptoms, impairment & risk (6 pathways)

MILESTONE

YOUNG PERSON VERSION

Title Transition Readiness and Appropriateness Measure (TRAM)

Purpose Transition Decision-Making Tool

Introduction This section asks questions about factors that may be important in deciding whether young people are ready and appropriate for transition to adult mental health services (AMHS). Responses will contribute to an informed decision regarding the most suitable mental healthcare service for you following discharge from child and adolescent mental health services (CAMHS). Alternatives to transition to AMHS may include short-term continuation with CAMHS, discharge to a family doctor (GP) or full discharge.

Functioning Related to the Transition Process
Please select the response that best describes you and your situation.
If more than one answer applies, please select the least problematic option from those that you are considering.

Are you able to act as an independent adult?
Acting as an independent adult incorporates being confident in talking to clinicians without parents/carers present and being able to make your own decisions about treatment.

Am fully able	Have some ability	Have limited ability	Am not able

Do you understand your mental health condition?
Understanding a mental health condition involves understanding possible triggers, treatment options and the consequences of not undergoing treatment.

Have full understanding	Have some understanding	Have little understanding	Have no clear understanding

Do you know how to access mental health services?
Accessing mental health services includes knowing how to book/cancel appointments, renew prescriptions, access services during transition and in a crisis, and knowledge of how the health system works.

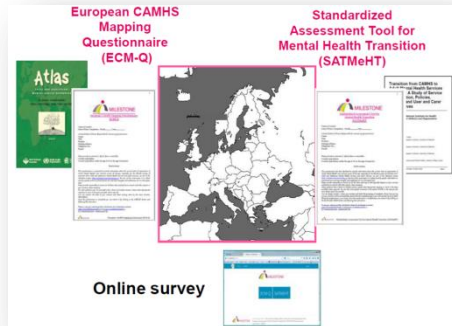
Have full knowledge	Have some knowledge	Have little knowledge	Have no clear knowledge

Are you motivated to manage your mental health condition?
Being motivated to manage your condition involves attending appointments, contributing to discussions, following advice of the treatment team and persisting when treatments take time to produce results.

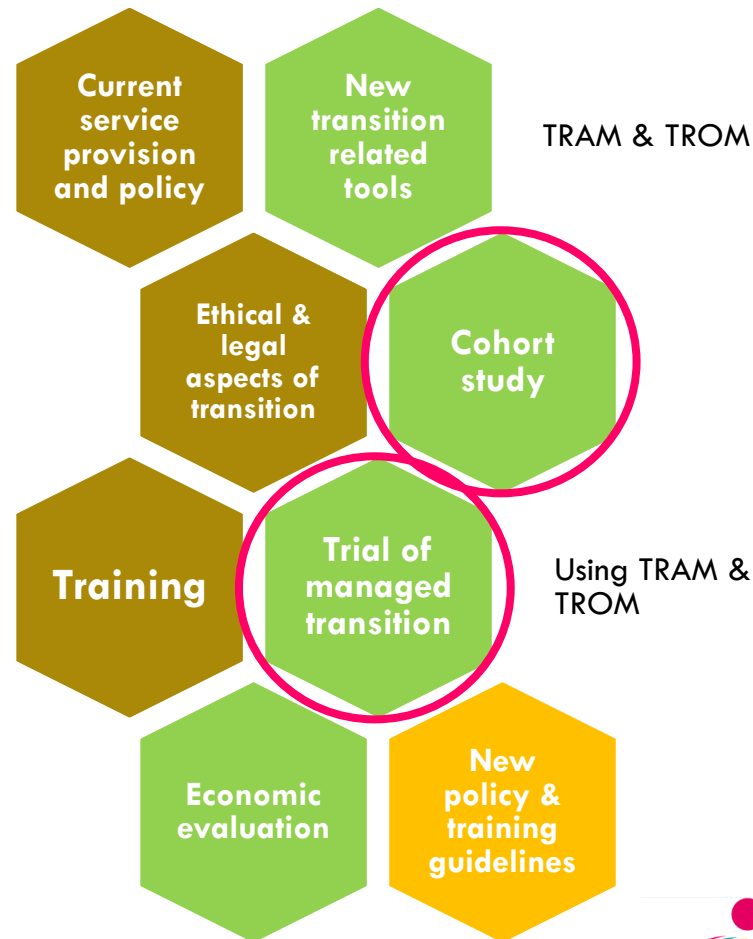
Show full motivation	Show some motivation	Show little motivation	Show no motivation

Doc: TRAM Young Person Version 2.12. 20150420
Study title: The MILESTONE Study: improving transition from CAMHS to AMHS v1.1

Themes covered by MILESTONE



Giulia Signorini &
Giovanni de Girolamo
Italy



TRAM = Transition Readiness and Appropriateness Measure
TROM = Transition Related Outcome Measure



“MILESTONE study”

- Follow-up of YP reaching end of care at CAMHS
- 24 months
- YPs outcomes & experiences

Prospective cohort study



- Testing TRAM as part of ‘managed transition’
- Does clinical support & assessment tool improve YPs outcomes & experiences?

Clinical trial

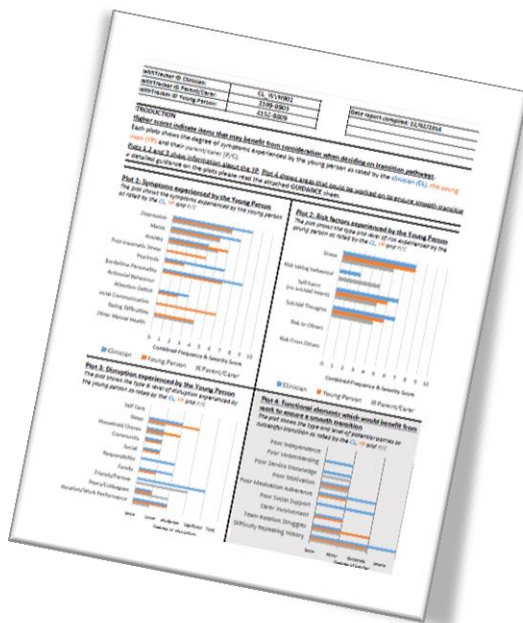


- Effectiveness & cost-effectiveness of managed transition

Economic evaluation



‘Managed transition’



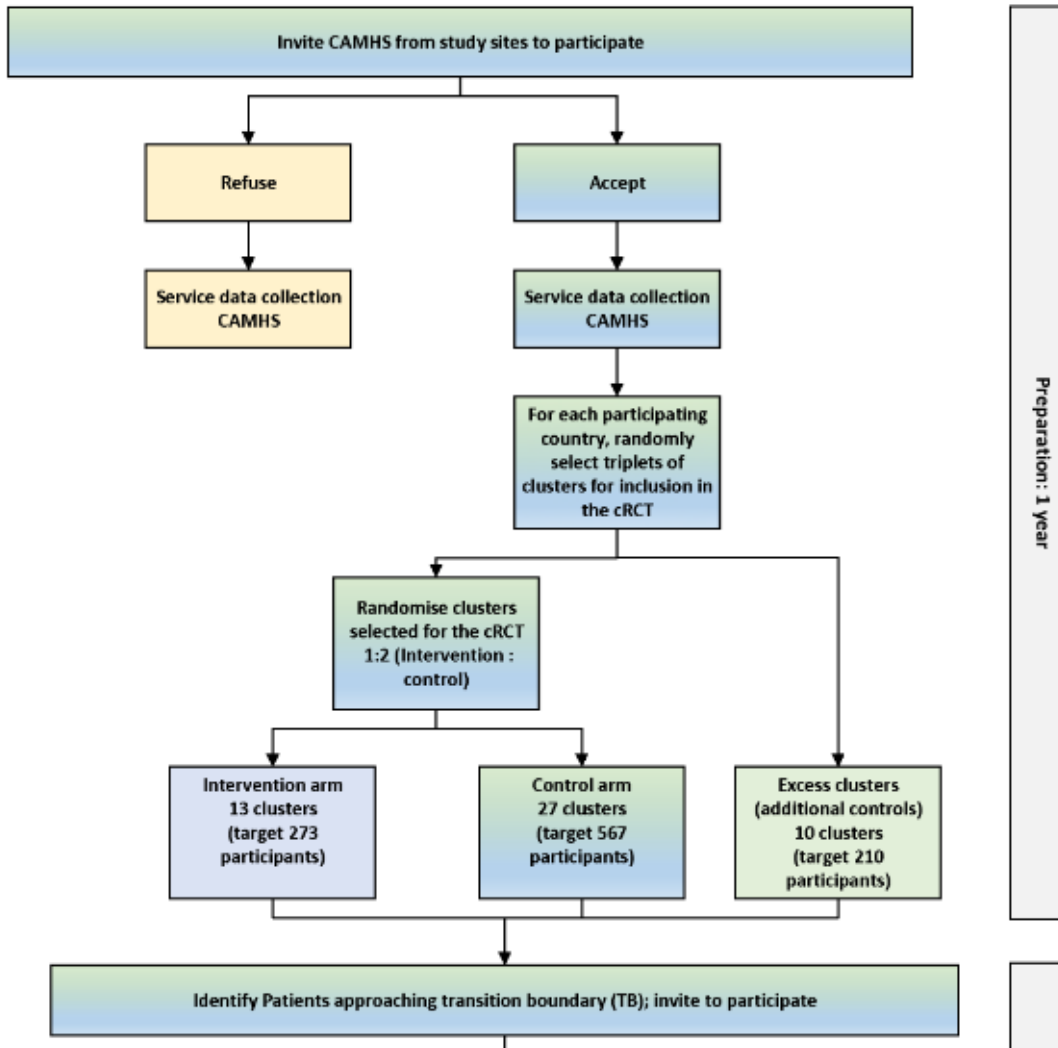
‘Managed transition’

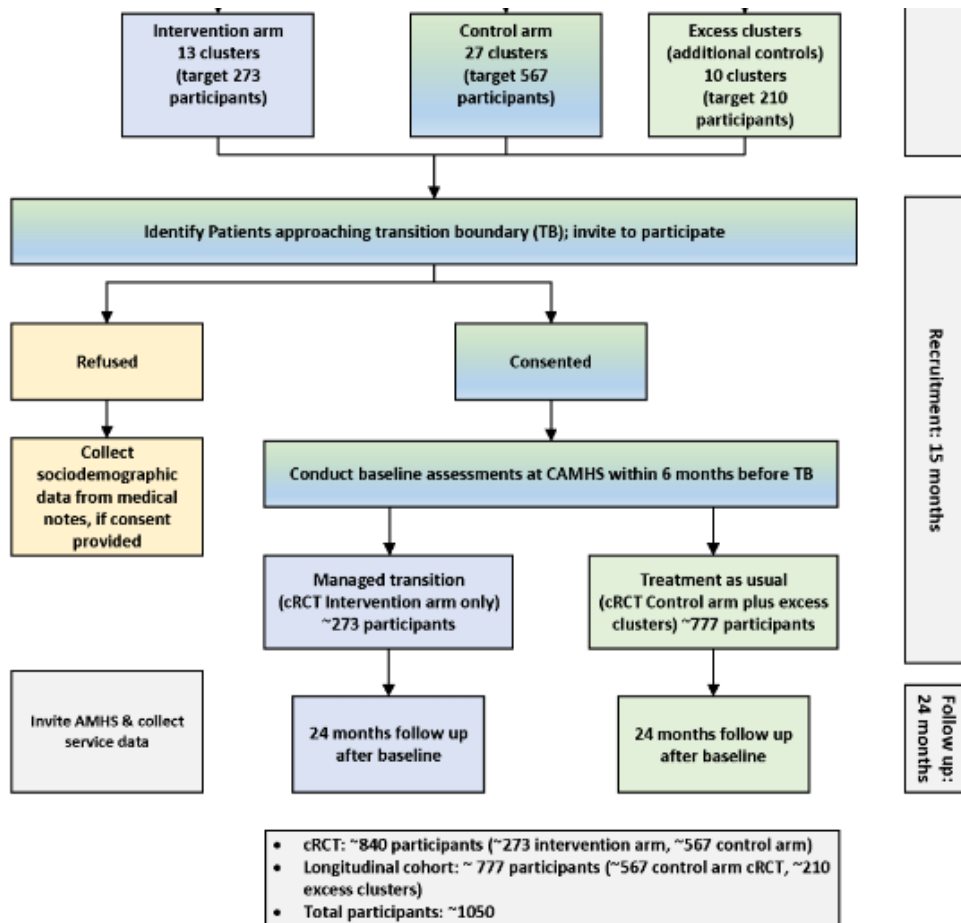
- TRAM score summary report
- YP, P/C & CI views
- Mental health & bio-psychosocial profile
- Supports: tailoring of transition plan - goals for critical items
- Communication

- **Involves** YP and PCs in the planning of transition in a timely fashion
- **Tailors** transition support to individual needs
- **Identifies barriers** to smooth transition and act on these
- Produces a succinct **medical summary** or profile of the service user
- **Improves information transfer and communication** with adult providers

(NICE guidelines, 2016)

MILESTONE study

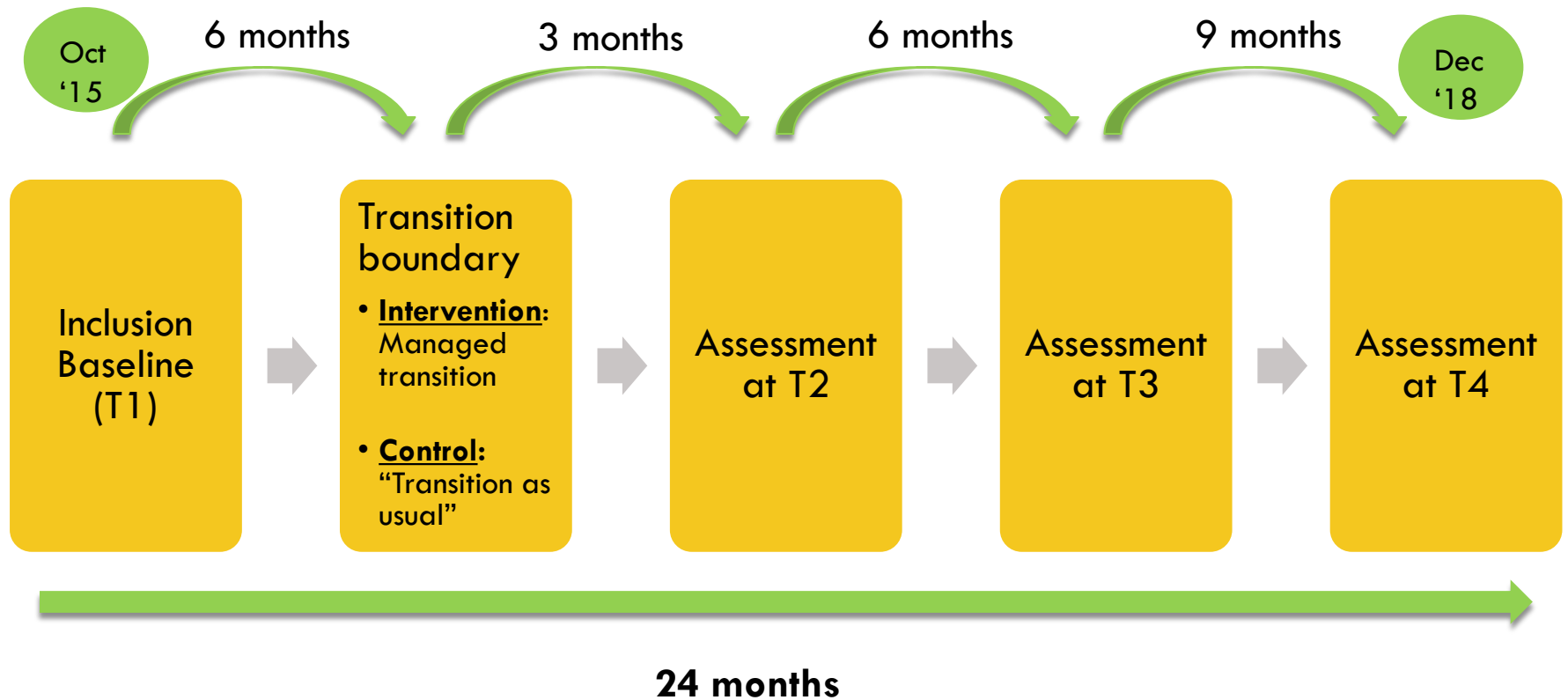




Eligibility criteria

1. If age is within one year of reaching the CAMHS TB (in exceptional cases, not more than 3 months older than the TB)
2. Has a mental disorder defined by DSM-IV-TR, DSM-5 or ICD 10/11, or is under the regular care of CAMHS (if not yet diagnosed)
3. Has an IQ ≥ 70 (ascertained by previous standardized assessment or diagnosed by clinician) or no indication of intellectual impairment

MILESTONE study - schedule



Young people, parents/carers and clinicians completed interviews and questionnaires at all timepoints

Learning from MILESTONE

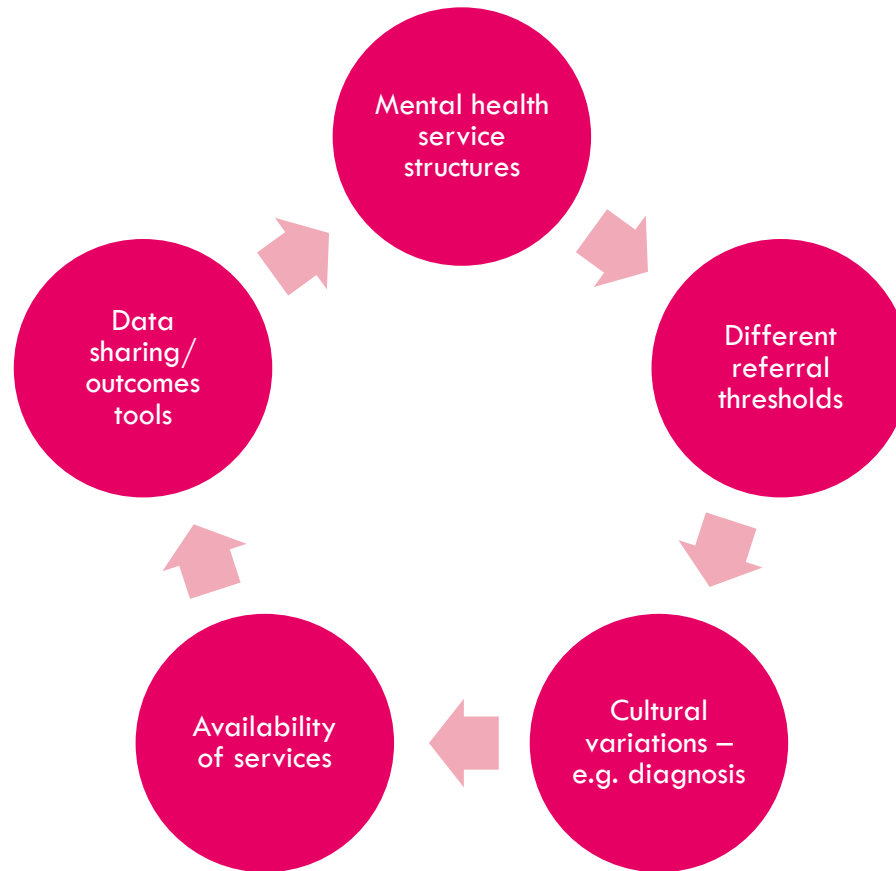


Learning from MILESTONE: the challenges of delivering a 5-year study across different countries

MILESTONE involved a longitudinal and a Randomised Control Trial - posed particular demands re:

1. Inclusion/exclusion criteria
2. Site selection - the same choice of sites not possible in every country
3. Ethics approvals
4. Young people involved over a lengthy period - keeping in touch with those with transient lifestyles.... or changing mental health needs.... could be hard. Plus issues about 'appropriateness'

Country differences - a lot to take account of



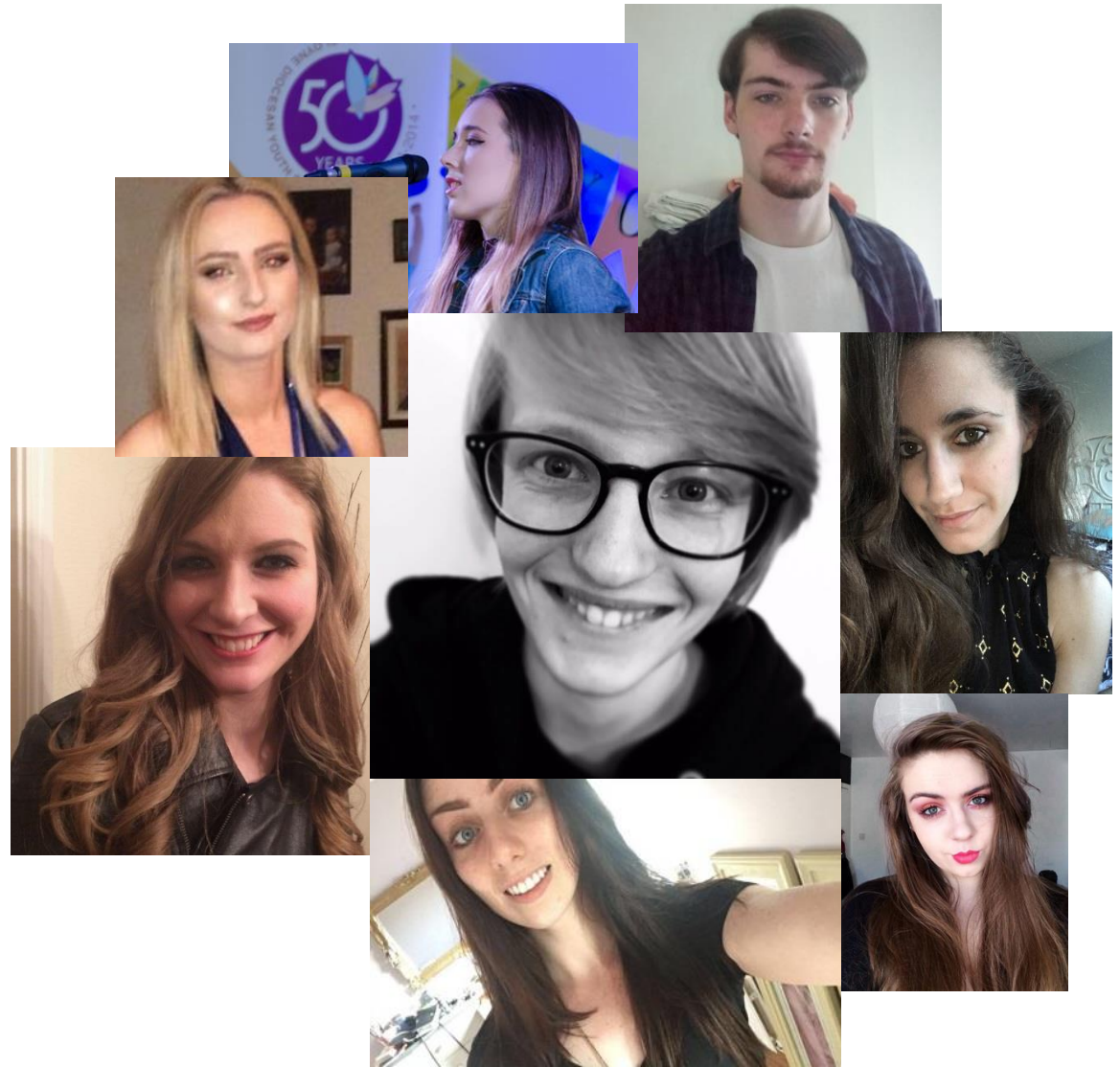
Other considerations

- **Engaging busy clinicians** - always a challenge but especially so over a long time period
- **Large quantity of data** - time for cleaning, analysis
- **Relevance of findings** - different countries have different interests, service priorities etc
- **Taking account of changes** - e.g. new initiatives, inquiries, policy and legislation
- **Maintaining the research team** - changes of personnel to be expected!

Discussion



PPI: Patient & Public Involvement



PPI in MILESTONE

- Patient and public involvement (PPI) lead costed in as a PI, responsible for recruiting and supporting young people and parents/carers
- Young people from the UK consulted from the very beginning during bid writing and development of the study methodology – ‘road-tested’ the draft tools
- Terms of reference (ToR) and one-year renewable sessional contracts for Young Project Advisors (YPAs)
- 4 young people from across the UK recruited early 2015; 6 young people from Ireland and a group of around 8-10 parents and carers, joined the project in later years

Why involve young people in research about mental health services?

In the UK, strong policy background encouraging 'service user' involvement - learning from 'experts by experience' helps to make sure that research is:

- **Relevant** – considers the issues that are important to those using services (which may not always be obvious to professionals!)
- **Up-to-date** – picks up on current or emerging issues
- **Not too burdensome** – e.g. data gathering is sensitive to the needs and life commitments of research participants
- **Accessible** - to those who might benefit from the findings/learning; e.g. avoids using clinical jargon, clear and precise outputs
- **Interactive** – establishes and builds strong relationships between clinicians and patients/carers

In MILESTONE, young advisors.....

Reviewed draft project tools to ensure language young-person appropriate; questions relevant; scoring understandable

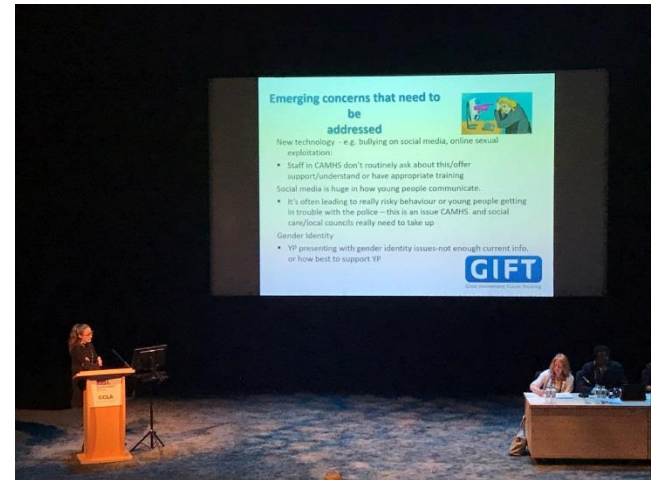
Designed project leaflets, postcards, thank you cards, newsletter and resources for the project website

Attended all key study meetings to review study progress and help think through any issues/problems

Co-produced range of outputs for public engagement and dissemination events – short films, blogs, journal articles

Reviewed findings, ran workshops, gave presentations and chaired events

Examples...



The benefits of PPI in research?

For service users

- Opportunity to share real life experience – a ‘voice’
- Sense of empowerment – being heard, confidence building
- New transferable skills

For researchers

- Insights from an important/different perspective
- Can help with recruitment, retention (new thinking on methods?)
- A check on researcher assumptions

For health practitioners

- Research findings that are ‘grounded’ in experiences – more relevant, acceptable, effective and/or practical?
- Supports collaborative approaches to solving problems

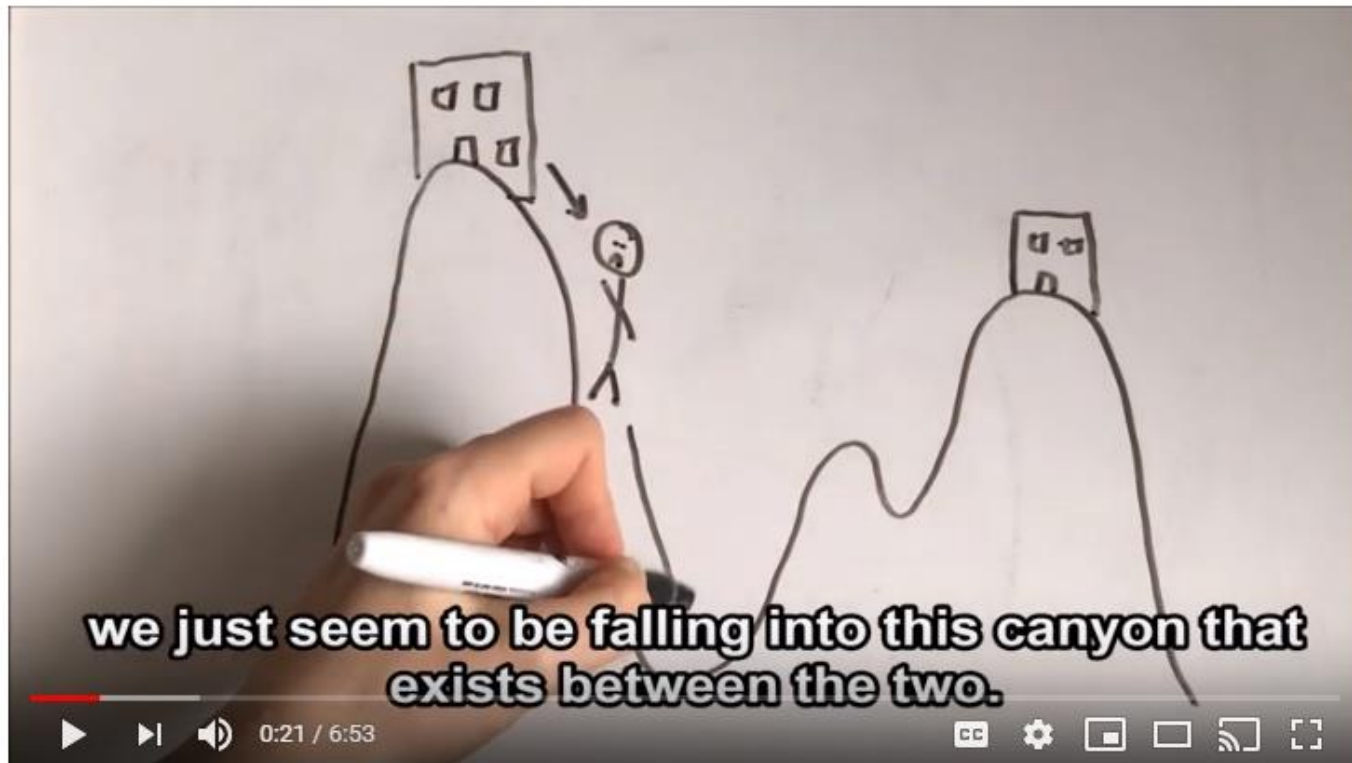
Young people's perspectives

Why it's important that young people are involved in research about MH services:

“Involving those who use services is the only way services can truly reflect current needs..... involving YPs in research really connects up research and reality. The voice of lived experience is very powerful”

“If participation in research didn't exist, there would be no voice for young people, they would feel marginalised... Being involved in research relies on the willingness to learn and evolve health care. But without this motivation, care would become stagnant or even deteriorate. It's imperative to the parity of esteem cause and stigma surrounding mental health”

Crossing the Canyon – film by the YPAs



Crossing the Canyon: Transition (by the MILESTONE Young Advisors)

Young Project Advisor's views:

“I was interested in joining the advisors group as I **am passionate about service development**. I also feel my transition was messy and unjust so I wanted to highlight how easily things can go wrong if services aren't integrated and equally how simple getting a good transition can be”

“I wanted to take my **bad experience and use it in the hope of improving things for other young people**. There is something powerful in recovery about ‘giving back.’”

“Trying to access MH services can be a difficult or daunting process and it's important for young service users to know that people like them, who have experience of using these services, were involved in research as it... **perhaps legitimises the results to the general public**”

What did the PPI in MILESTONE achieve?

National awareness of the issue..... the MILESTONE YPAs:

Articles published, e.g., in Lancet Psychiatry May 2015

Input at a wide variety of conferences – in Ireland, Italy, Norway, London, Birmingham and Prague to name but a few!

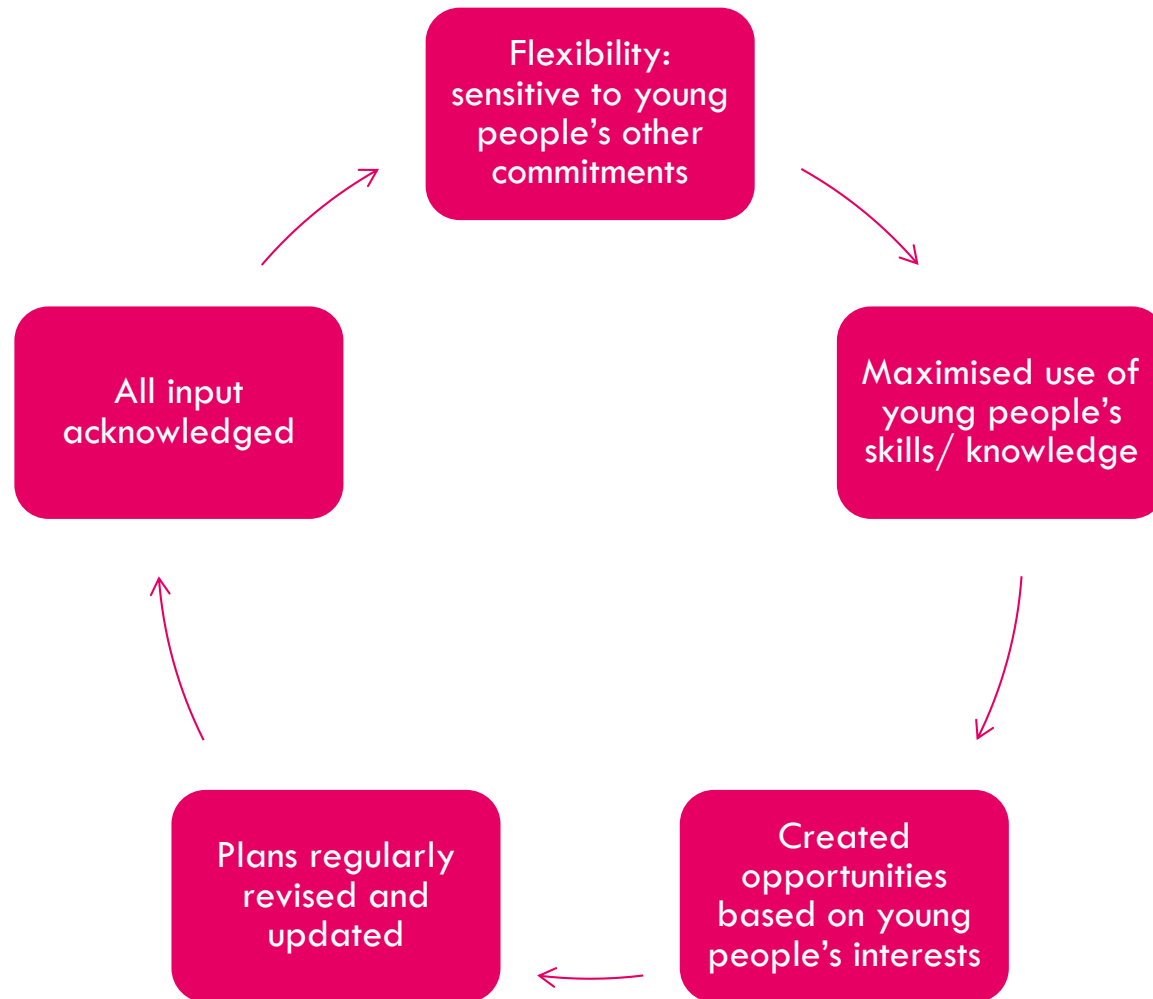
Invited to high level policy meetings about mental health and transition – e.g. met the UK Shadow Minister for Mental Health in 2016 and spoke to senior elected members of the Local Government Association

Won MQ and National Institute for Health Research (NIHR) Service User Involvement in Research Award in 2016

Views on impact

- “It was wonderful to know that our opinions were important and validated.... It’s a great experience to get the chance to be involved (in MH research) and to see so many others working towards the same goal to make transition and services better for the future...”
- “I got to apply learning from personal experience to a project that stands to help thousands of young people across Europe”
- “Gave me so much confidence, confidence that I never had before in my abilities. It showed me that I am more than my diagnosis.... Overall, it helped me in my personal recovery”
- “able to express my opinions in a safe environment.... Made friends and learned so much about research and ethics...”

Key principles of MILESTONE's PPI



Key learning points

Involving young people as advisors in MILESTONE definitely benefitted the study, in particular:

The early role in testing and refining the study tools

Later on, using creative methods and developing accessible outputs for dissemination (films, poetry, social media etc)

Very important:

Having a named person overseeing all PPI activities (to ensure opportunities shared, no one individual over-loaded etc)

Having a sessional contract with Warwick University and agreed rates of pay and hours gave the role of *Young Project Advisors (YPAs)* status and security within the project team

But there were some challenges.....

The challenges

Being heard in a large research group

- Dealing with different languages, cultures
- Varying levels of co-production expertise
- Time pressures – including YP's other commitments

Study topic highly sensitive

- Could be triggering or painful
- Need for careful planning, support and debriefing
- Being sensitive to young people's own health situation/history

Logistics of international study

- Travel, e.g. flights, delays potentially stressful
- Ability/confidence of YPs to travel on their own (and minimising need for solo travel)
- Expenses

What would you do differently?

“ Learn from the
mistakes
of others. You
can't live long
enough to make
them all yourself. ”

Eleanor Roosevelt