Ethical aspects in Transition: Results from Eu MILESTONE Project

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Disclosure

None, other than…

EU 7th Framework Programme

Lost my voice Monday…

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Applying ethical principles to Transition

Importance of continuity of care for youth with MH needs

Aware of the GAP in service & any efforts to address this need to be set in the context of good ethical principles.

- **Justice**: Ensure best use of limited resources
  - Fairness. Investment in one service often at expense of other
- **Beneficence**:
  - Ensure we do good. In our efforts to FIX, including Managed Transition (MILESTONE Main Study) it must be beneficial
- **Non-maleficence**:
  - Ensure we do no harm: Are we sure that by facilitating transition, there are no unintended consequences of 'pathologizing transient & self-limiting distress and dysfunction which may be normal during adolescence?'
- **Autonomy**:
  - Ensure we give youth appropriate autonomy. Involving youth in the Decision process

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Paul et al. BMC Medical Ethics (2018) 19:73
https://doi.org/10.1186/s12910-018-0276-3

BMC Medical Ethics

RESEARCH ARTICLE Open Access

A systematic review of the literature on ethical aspects of transitional care between child- and adult-orientated health services

Moli Paul[1,2*], Lesley O'Hara[3], Priya Tah[1], Cathy Street[1], Athanasios Maras[4], Diane Purper Ouakil[5], Paramala Santosh[6], Giulia Signorini[7], Swaran Preet Singh[1], Helena Tuomainen[1], Fiona McNicholas[8,9,10] and the MILESTONE Consortium

Search terms:
Transition, Adolescence, Mental Health, Ethics

6 studies found:
None on MH, all focussed on the needs of YP with complex care needs & disabilities

Need to gather data ....

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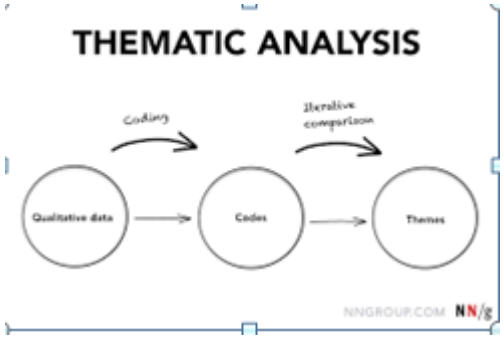
Round 1:
Focus Groups
Pre-Milestone baseline
To inform questionnaire



Sites: Dublin, Warwick and Split. (4 each site)	Participant Demographics	Qualitative Analysis:
• 2 x MH & 2 x Youth advocacy group • Embedded ethical issues into vignettes • Different types of MH need, age, social support etc	• N = 111 • (17 M, 94 F) • Age range16 – 60 • Personal experience of MH difficulties: 34 • Someone close to them with MH difficulties: 55	• To try and ID possible ethical issues around transition • Case vignettes facilitating discussion • Grounded theory approach • Line-by-line coding • Grouping similar codes into clusters • Constructing theory from the bottom up

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Qualitative analysis & Central Themes

- **Central themes:**
- 1. Autonomy & Informed Decision-making
  - The tension between professional (& at times parental) paternalism & YPs' growing autonomy was well captured in terms of extent & process
  - Importance of knowledge transfer & information exchange at the TB
- 2. Stigma & Labelling
  - A potential barrier to service access

'He is marked

Retelling, again & again

Locked up

Embarrassment

Don't use words or phrases that young people find difficult to understand

Looney Bi

Feed her all that you can with the information

Give the family information too

Action:

Designed Ethics Questionnaire

POWER TRUST PRESSURE

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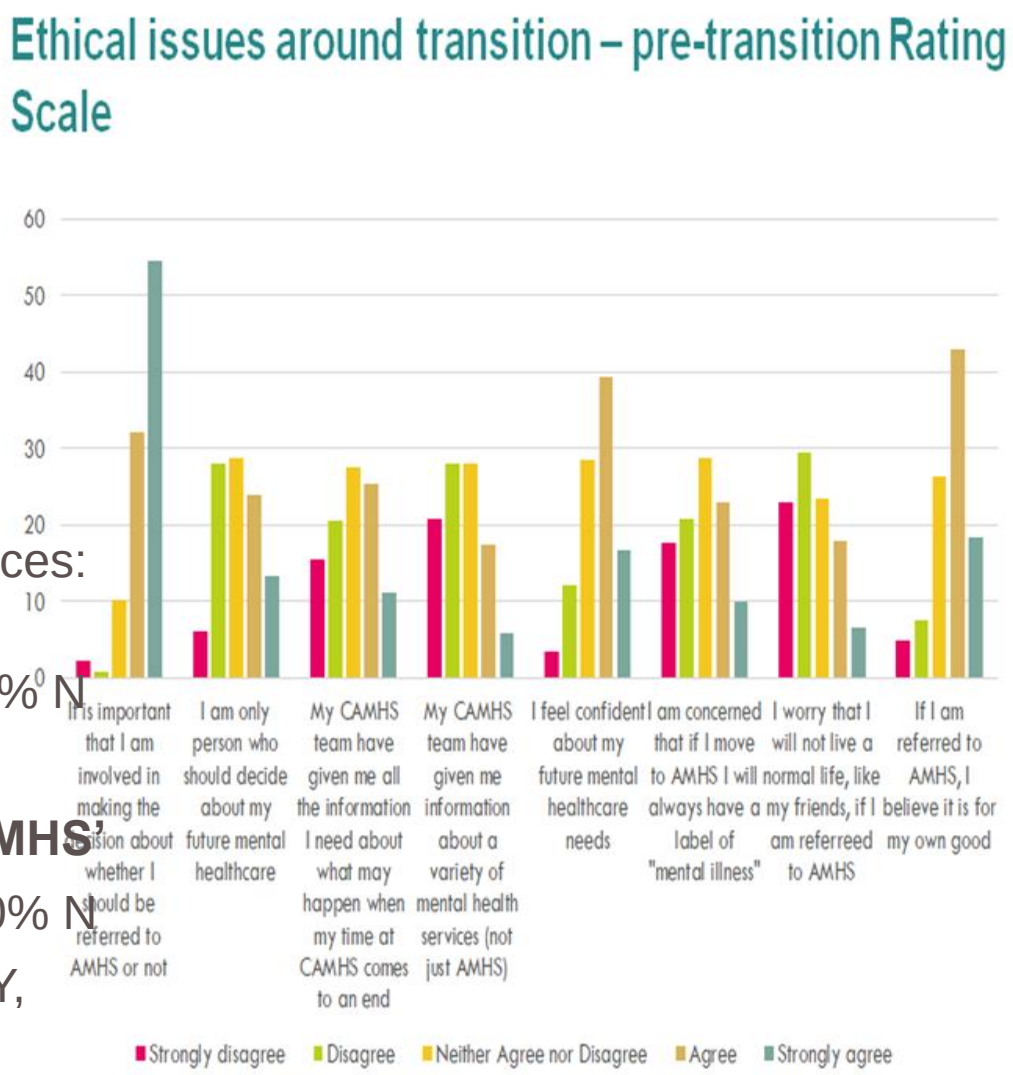
Baseline Ethics Questionnaire (8 Q) N=1060 YP, 16-18 at TB

- Being involved: Important Y 85%
- **Only** person to decide 37% Y

- **Are they prepared & informed….**
- Spilt: 37% Y 36% N
- Aware of other non-AMHS MH- services: 50% Y 20% N
- Future MH care confident: 55% Y 15% N

- **Personal Meaning of 'referral to AMHS'**
- Fear of Lifelong MI Label: 33% Y, 40% N
- Fear of not living a normal life: 20% Y, 50% N
- Belief for own good 60% Y 10% N.



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Round 2 FG : 12-15m Post TB
YP and P/C (N=54)
Aim: To gather the views of YP, parents /carers about the transition period including any ethical challenges they faced.

We kept the topic guide flexible to let people tell us what mattered to them

What was your **experience of CAMHS** and leaving it?

What would have been **your ideal experience**?

What is your experience of **your current service provision?**

What would be your **ideal experience**?

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Sample: 4 countries Ireland, NL, UK, Croatia (N=56)

	YP	Parents	Service	Diagnosis
Ireland	8	5 + 1 carer	8 with no service, 3 at GP, 2 in CAMHS	Depression, Anxiety, ADHD, BPD, OCD
Netherlands	9	0	7 with no service, 2 in AMHS	Depression, ADHD, PTSD, Anxiety, Autism, Eating disorder, Attachment disorder (3 with multiple)
Croatia	8	12	11 with no service, 1 in CAMHS	Anxiety, conduct, psychoses, Depression,(5 with multiple)
London	3		3 with no services (1 on waiting list for AMHS)	BPD, Anorexia, OCD/Phobias
Midlands	6	4	9 with no service, 1 in AMHS	ASD, Anorexia, Anxiety, Depression, Suicidality
Total	**34**	**22**	**4 in (or WL) AMHS, 2 still in CAMHS, 3 with GP, 37 no MH service (79%)** ***Only 10% of cohort (N=1060) ended up in AMHS***	

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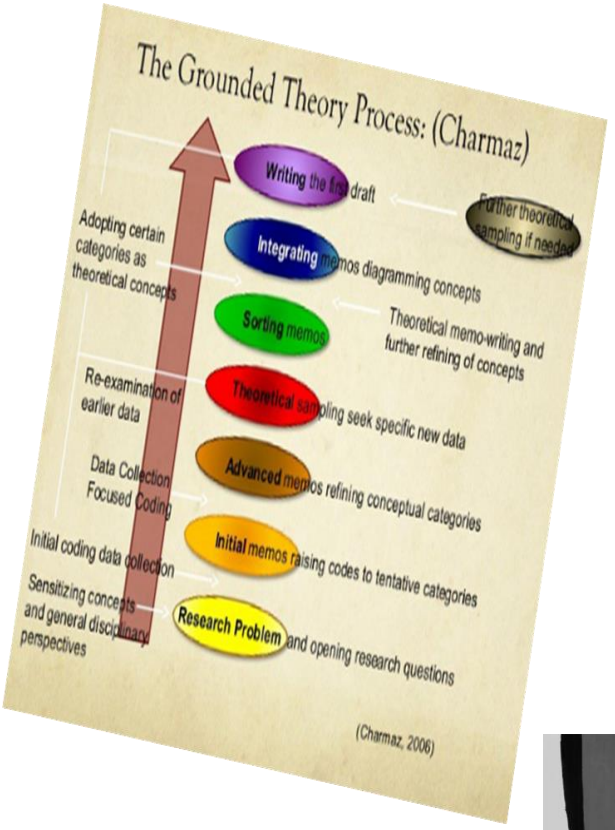
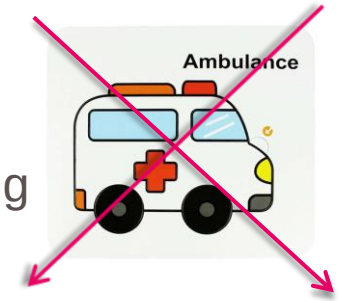
1. What was your experience like of CAMHS?



- Generally positive
  - Formed warm relationships with therapist
  - Supported by parent(s) or carers
- Negative experience connected to
  - Lack of services especially out of hours
  - Too little autonomy
  - Not being listened to
  - Paternalistic decision making
  - Role of parent (too little/too much/outside their control)



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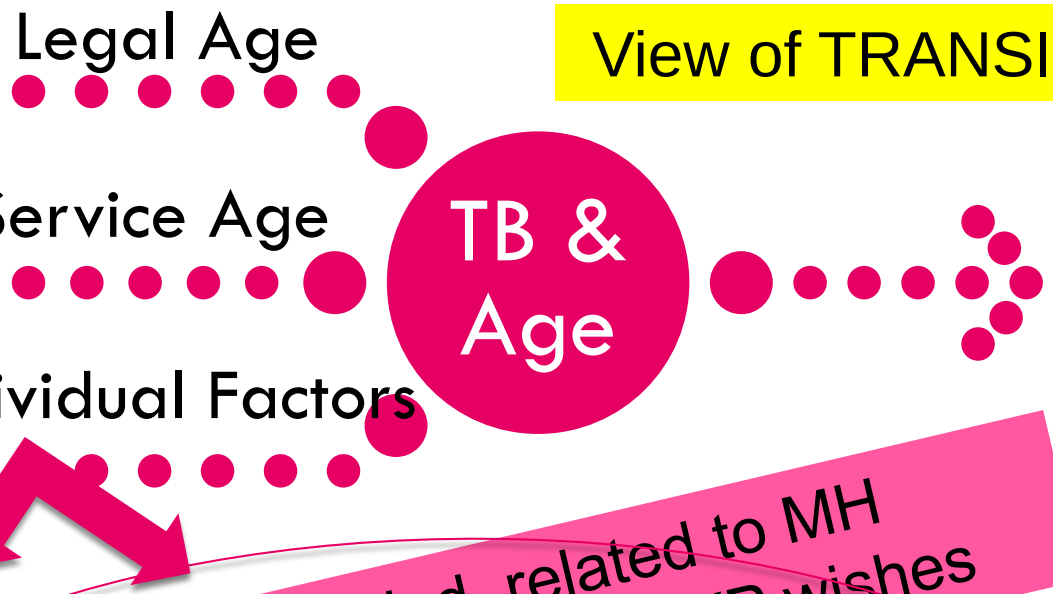
View of TRANSITION



I am 18 but I still feel like a child in my head

They decided I'd have 1 last session…so I had to end it, which I didn't want to, but I had to"

Much more nuanced: Flexible, Varied, related to MH wellbeing at time, Quality of preceding care, YP wishes

kind of unprepared

"I don't think even age comes into it. I think a 50 year old person, if they have been discharged from anywhere, should have the person who's going to look after their welfare beside them'

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Diagnosis & Label:
Mixed, varied
Often in same person

- **Positive**
- Access to care/service
- Access to treatment
- Understanding
- Self-Identify

That label could be handy

Can produce acceptance

Working towards a goal

It's just a part of who I am

I already have enough labels

Treatment was only directed towards my diagnosis

I felt like a walking diagnosis

I'm stuck with it my whole life

- **Negative**
- Stigmatising
- Fixed & Life long
- Excessive, numerous
- Can be given or taken away
- Dehumanising /objectifying

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What is your Experience of current service provision

- Most not in any MH service (78%), very few in AMHS (<10%)
- Many on medication
  - But had to find GP
  - Pay for appointments & scripts
- Some on Waiting lists for AMHS
- Some referred to 3rd sector, voluntary organisations, crisis lines, web sites

- Advice offered may have been well meaning but was negatively perceived by some youth
  - Esp. re use of 3rd party services
  - Felt '***fobbed off***"

I actually wouldn't be as comfortable to see them…I'd rather see a professional

He was like, "Just go to any GP that can help you. You can go online" & all that stuff, that's all."

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What would have been your ideal experience?

When in CAMHS

- **More input in decision making** (if parents should be in the room, when confidentiality should be broken and the process around this)
- **More choice (**types of therapy/ frequency of OPD)
- **More information** (about medication, other (post MH) services,
- **Flexibility** about age boundary

obviously she's an adult & the GPs don't want to talk to me anymore P

Movement out of CAMHS

- More **meaningful information that travels** between services, a plan for coming off/adapting medication
- Shorter waiting lists
- Easy re-entry

- **Option for parents and/or SOs to be involved** in adult care
- **Not being 'referred' to 3rd sector carelines**
- **Safety net** including being able to phone up later if they need a recommendation for who to see

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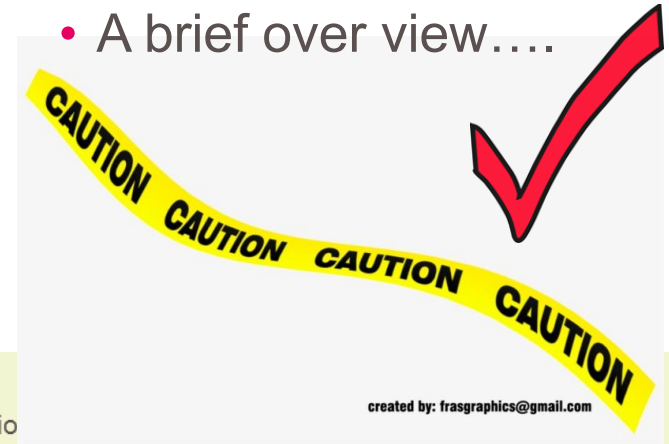
QUANTITATIVE DATA POST TB

- The cohort (N=749, 94%) completed baseline Ethics questions regarding ethical aspects of transitioning,
  - including their role in decision making, perceptions and confidence in health care provision and impact of referral.
- Total sample N= 749
  - **Referred to AMHS: 20%** (N=153/749)
- **RCT Arm: N=464, referred 16.4%** (76/464)
  - Mx care: 16.3% (N= 28/172)
  - TAU: 16.4% (N=48/292)
- No difference in BASELINE ethics Q SCORES between groups, but YP in intervention arm a little more unwell on average at randomisation

- Some cautionary notes ahead of data:
- Have not adequately (as yet) adjusted for the design variables (country, cluster, time point and person) or baseline characteristics (diagnosis/illness severity in particular)
- A brief over view….



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QUANTITATIVE DATA BASELINE

Table 1: Baseline questionnaire Total N= 749	Disagree	Unsure	Agree
Q1: It is important that I am involved in the decision about whether I should be referred to AMHS or not	3%	2510%	**87%**
Q2 I am the ONLY person who should decide about my future MH care	35%	29%	**37%**
Q3 My CAMHS team have given me all the information I need when my time at CAMHS comes to an end.	36%	28%	**37%**
Q4. My CAMHS team have given me information about a variety of MH services (not just AMHS)	49%	28%	**23%**
Q5 I feel confident about deciding about my future MH care needs	**16%**	28%	56%
Q6 I am concerned that if I move to AMHS I will always have a label of mental illness.	**38%**	29%	33%
Q7 I worry that I will not have a normal life, like my friends if I am referred to AMHS	**52%**	**23%**	24%
Q8 If I am referred to AMHS I believe it is for my own good	12%	26%	**61%**

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QUANTITATIVE DATA 15M + POST TB

Table 1: FU questionnaire on Ethical Aspects of MH care. T3/T4: Total N= 524 (70% original sample)	Disagree	Unsure	Agree
Q1: I was involved in the decision about what would happen when my time at CAMHS came to an end.	13%	25%	**64%**
Q2 I was able to make my own decision about whether I should move to AMHS or not.	18%	25%	**57%**
Q3 I knew what to expect when my time at CAMHS came to an end.	24%	27%	**49%**
Q4 I received all the information I needed about the variety of MH services available to me once I left CAMHS.	**29%**	25%	46%
Q5 I do not feel that being in MH services has labelled me with a long-term mental illness.	**18%**	31%	51%
Q6 I feel like I have lived a normal life, like anyone else, since I left CAMHS	**24%**	**30%**	46%
Q7 I feel the decision made about my MH care was in my best interests.	9%	25%	**66%**

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Table 2: Ethical Q: % Agree If Referred (N=183)	Referred N=183, 23%
Q1: Involved in decision post CAMHS	↓* (61%)
Q2 Make own decision about referral to AMHS	↓* (54%)
Q3 Knowledge post CAMHS	↓ (41%)
Q4 Information Other MH services post CAMHS	↓ (38%)
Q5 Confident re no label of long-term MI	↓ (33%)
Q6 Lived normal life post CAMHS	↓ (39%)
Q7 MH care decision in Own best interest	↓ (61%)

Referrals
N=183, 23%

It Referred: *generally more negative*

Linked with significant decrease in being involved, & making their own decision and of treatment decisions being in their best interest

Trend towards poorer views on Risk of Label, not being able to live a normal life, and receiving less information

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Table 3: Was there any difference in perspectives in Mx care versus TAU?	Mx Care N=144	TAU N=320
Q1: Involved in decision post CAMHS	72% all ↑*	67% all
Q2 Make own decision about referral to AMHS	72% all	67% all
Q3 Knowledge post CAMHS	61% all ↑	49% all
Q4 Information Other MH services post CAMHS	60% all ↑*	43% all
Q5 Do Not believe Referral linked with label of long-term MI	58% all ↑	51% all
Q6 Lived normal life post CAMHS	52% all ↑	49% all
Q7 MH care decision Own best interest	72% all ↑	63% all

Managed Care

Managed Care: *in general positive*

- Significant ↑ in being involved & informed about other MH service options
- Trend ↑ own decision, normal life & best interest; less fear re label

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Table 4: Limiting analysis to the RCT referred group N=76, did the benefit seen in Mx care versus TAU hold?	Mx Care N= 28	TAU N= 48
Q1: Involved in decision post CAMHS	61% R ↓*	67% R
Q2 Make own decision about referral to AMHS	61% R↓*	67% R
Q3 Knowledge post CAMHS	54% R↑*	33%R
Q4 Information Other MH services post CAMHS	57% R↑*	25%R
Q5 Do Not fear Referral label of long-term MI	43% R	46% R
Q6 Lived normal life post CAMHS	43% R↑	40% R
Q7 MH care decision Own best interest	54% R ↓	63%R

Managed Care and referred: *Mixed*

Benefits in significant ↑ in knowledge & Information, trend towards ↓stigmatization

BUT Possibly perceived as paternalistic: significant ↓ in personal agency: own decision & being involved

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Conclusion:

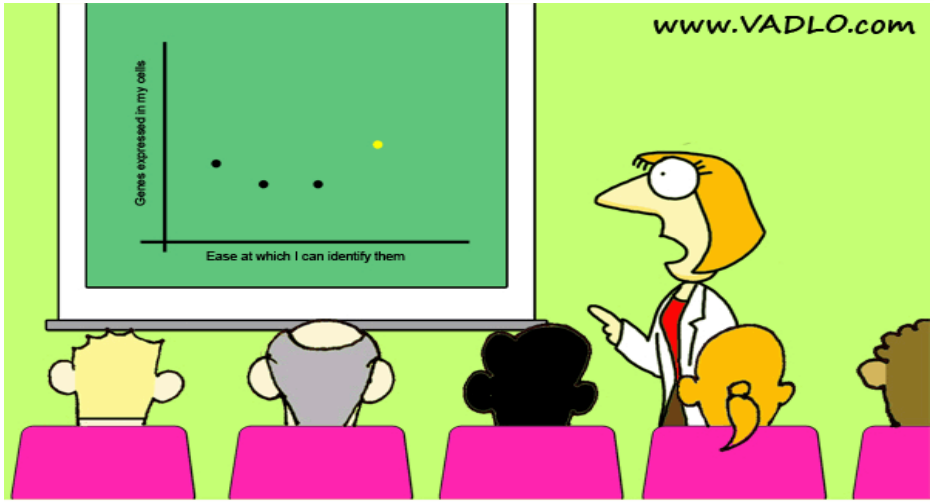
Ensure that any new service, innovation, improvement is tested by Youth and ethically sound.

Must be Fair, beneficial, does not harm and has youth central to process

Managed care: Generally beneficial, but also risk of lowering autonomy

We can not be complacent, we do not have not time….what do the young people tell us:

https://www.youtube.com/watch?v=nTs6p_s5Kgs#action=share



"Same graph as last year,
but now I have an additional dot."

Go raibh maith agat!

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YP Video on Transition

- https://www.youtube.com/watch?v=nTs6p_s5Kgs#action=share

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Table 2: Ethical Q If Referred (N=183), RCT N=464, and RCT Referral (N=76) % Agree	Referred N=183, 23%	Mx Care N=144	TAU N=320
Q1: Involved in decision post CAMHS	61% ↓*	72% all ↑* 61% R ↓*	67% all 67% R
Q2 Make own decision about referral to AMHS	54% ↓*	72% all 61% R↓*	67% all 67% R
Q3 Knowledge post CAMHS	41% ↓	61% all ↑ 54% R↑*	49% all 33%R
Q4 Information Other MH services post CAMHS	38% ↓	60% all ↑* 57% R↑*	43% all 25%R
Q5 Do Not fear Referral label of long-term MI	33% ↓	58% all ↑ 43% R	51% all 46% R
Q6 Lived normal life post CAMHS	39% ↓	52% all ↑ 43% R↑	49% all 40% R
Q7 MH care decision Own best interest	61% ↓	72% all ↑ 54% R ↓	63% all 63%R

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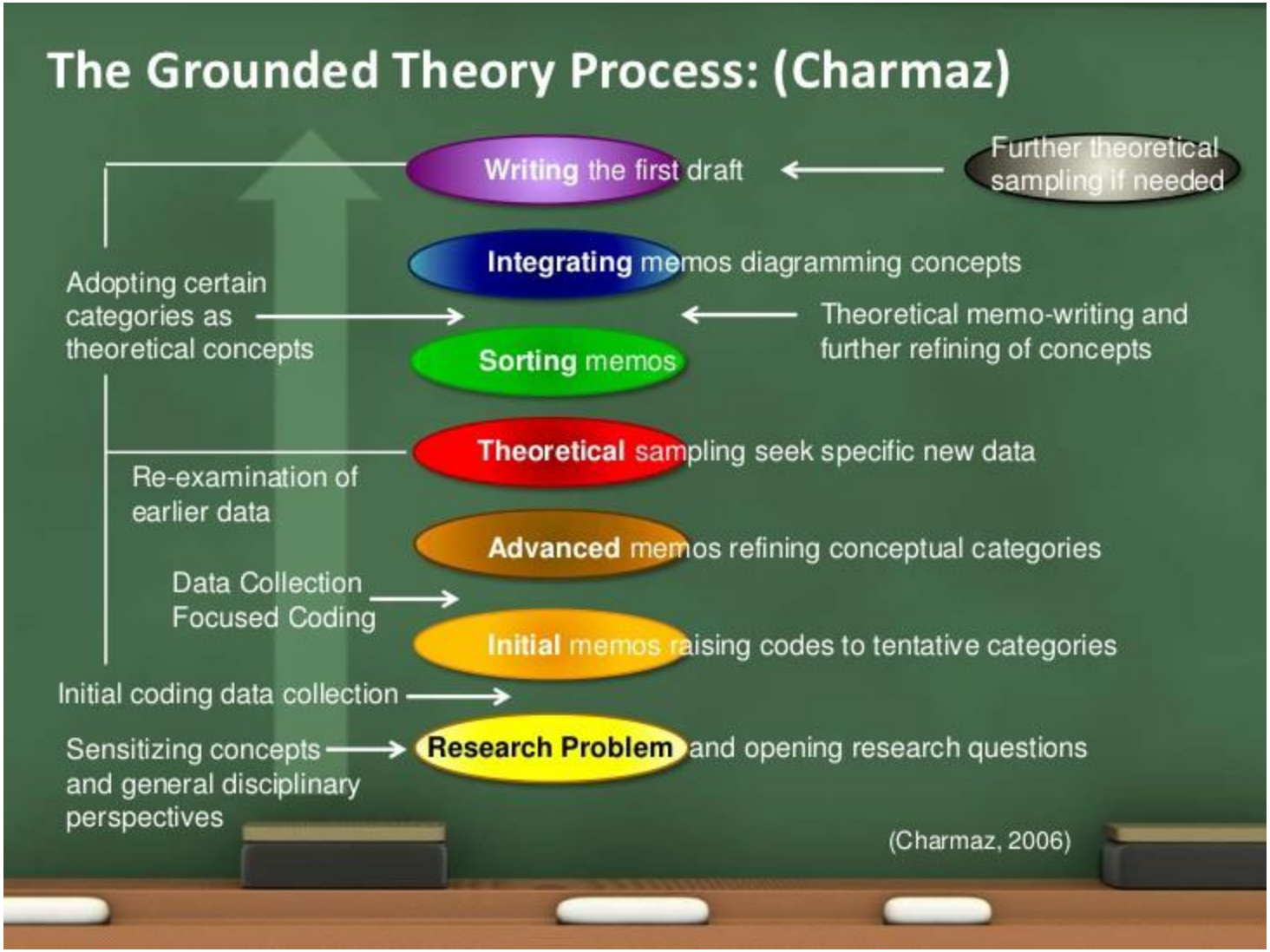

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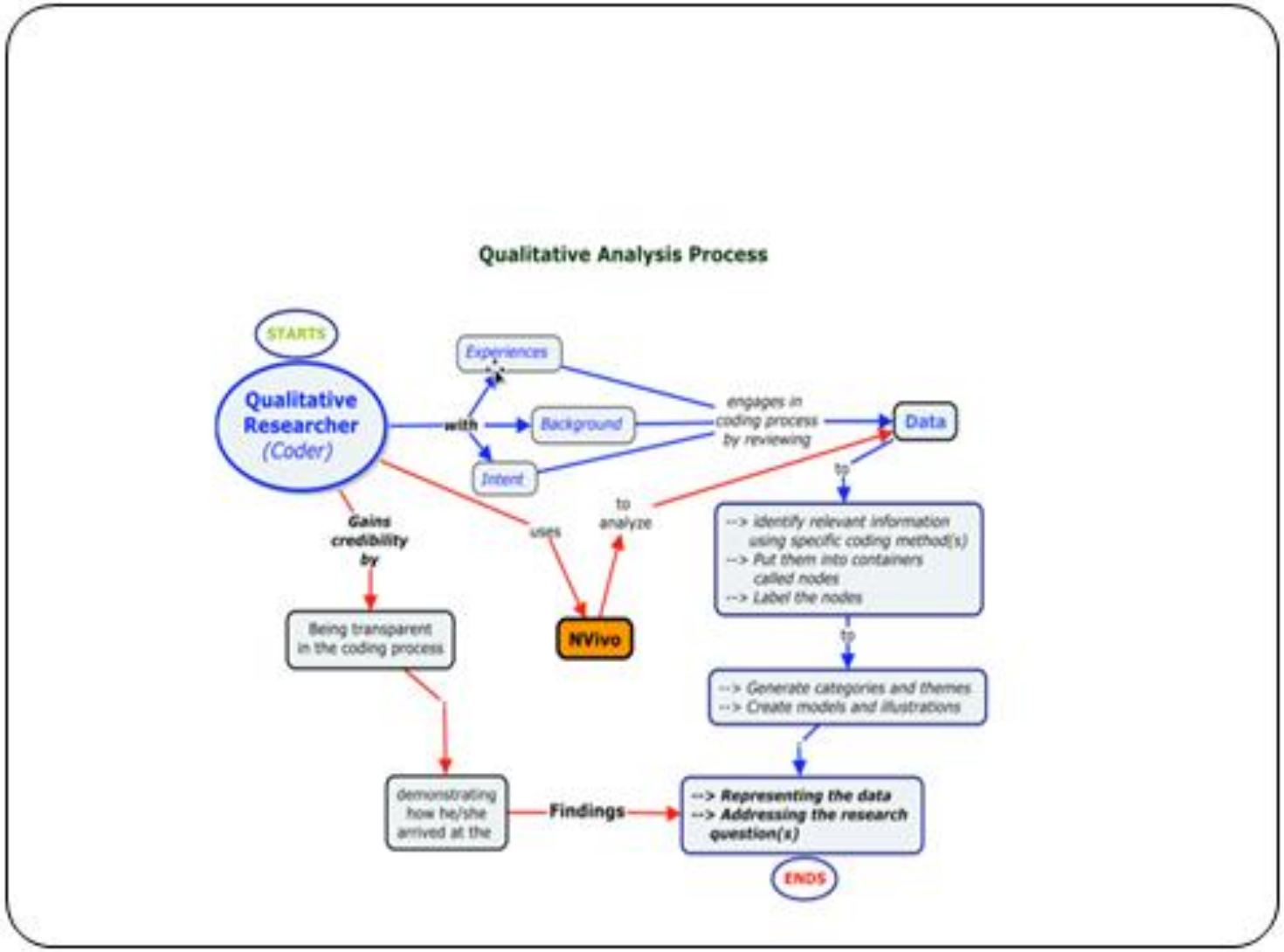

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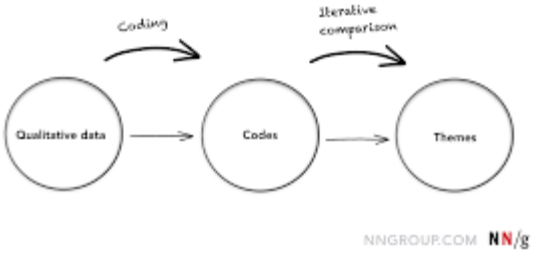
THEMATIC ANALYSIS



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