Community-based services for people with complex emotional needs

30th April 2021

NIHR mhpru Mental Health Policy Research Unit

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Acknowledgements

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About the Complex Emotional Needs Research Programme

- Conducted to help inform commitments in the 2018 NHS Long Term Plan, and support improved commissioning of services that support people with complex emotional needs.
- Informed by a working group of experts by experience and by occupation.
- Includes:
  - Scoping review and typology of community services for people with complex emotional needs
  - Systematic review of the characteristics that determine experiences and outcomes of community services for people with complex emotional needs
  - Systematic reviews and qualitative studies of service user and staff experiences of and perspectives
  - Systematic reviews of cost-effectiveness studies and economic modelling of service costs using routine data.

Agenda

When	What	Who
1.40-2.20	Presentation of research findings	Luke Sheridan Rains Kylee Trevillion Una Foye Paul McCrone
2.20-2.50	Implications for practice	Panel 1 – please add your questions to the chat box
2.50-3.00	Break	-
3.00-3.30	Implications for research	Panel 2 – please add your questions to the chat box
3.30-3.55	Implications and priorities	Breakout rooms – you will be automatically moved across
3.55-4.00	Closing remarks	Tina Coldham

Community Treatments for Complex Emotional Needs

A scoping review

Rationale

- There are several good quality reviews of psychotherapies for “borderline personality disorder” (e.g. 2020 Cochrane review)

- No reviews explore service models/good quality systems of care.

- Our questions:
  - How to have a good system of care with good continuity, accessibility, and therapeutic settings/relationships?
  - How to improve quality and embed helpful interventions in generic settings?
  - How to deliver trauma-focused care and help with social and practical aspects of people's lives?
  - What is the potential value of peer support and co-produced interventions?

Method

- Scoping review of studies of:
  - Any treatment that is offered in a community setting*, including psychotherapies, case management, and therapeutic communities, amongst others.
  - Conducted with adults (over 16's) with a diagnosis of any 'personality disorder' or experiencing symptoms or difficulties related to a diagnosis of 'personality disorder' (e.g., repeated self-harm).
  - Using any study design

* Forensic settings, crisis care, and inpatient care not included.

Findings – the state of the evidence

- Around 240 papers in 30 years identified – approx. half are RCTs of psychotherapies
- Studies conducted in a range of countries including USA, Canada, UK, Western Europe, Australia, and New Zealand.
- Preliminary results – there is evidence that **most specialist psychotherapies work:**
  - Few differences in head-to-head comparisons of specialist psychotherapies.
  - Substantial improvements seen in practically every study with any therapy.
  - RCTs and pre/post studies mostly evaluate same treatments, making pre-post studies largely redundant.

Findings – the gaps in the evidence

- Substantial and convincing studies lacking on most of our questions regarding good quality care in the community.

- Evidence for groups/treatments other than psychotherapy for “borderline personality disorder” is preliminary, often from uncontrolled feasibility trials.

- Only a handful of small studies that focus on:
  - Collaborative care/shared decision making
  - Helping get back to work or study after DBT
  - Interventions combining “borderline personality disorder” and trauma focus,
  - Young people or older people,
  - People who also have severe mental illness and substance abuse

Conclusions

- Preliminary evidence suggests that people engage and improve with treatment, but much **more evidence** is needed.

- Need for greater emphasis on **coproduced research** and **centring service users' and carers' priorities**, as identified in our other work.

- We know that conditions traditionally known as "personality disorder" have a lot of potential to be treatable – we now need to know more about **what works best for whom**.

Service user experiences and perspectives of community services for Complex Emotional Needs

A qualitative study and meta-synthesis

Qualitative interview study with service users

Aim:

To understand the experiences and views of people with relevant lived experiences regarding how community services can best meet the needs of people with complex emotional needs

Design:

30 adults with complex emotional needs related to characteristics of ‘personality disorder’ and/or a diagnosis of 'personality disorder' who may have used specialist community ‘personality disorder’ services (CPDS) or relevant statutory and non-statutory third-sector community services in England

Research team included Lived Experience Researchers

We sampled to include a diverse range of ages, sex, ethnicities, regional spread and use of community services

Service user experience meta-synthesis

Aim:

To systematically review and synthesise qualitative studies on service user experiences of community mental health care for Complex Emotional Needs.

Design:

Systematic review and meta-synthesis of international literature on service user experiences of community MH services for CEN published since 2003.

47 papers identified including 1,531 service users. 28 papers from UK. Most others were from elsewhere in Europe, Australia, or USA.

Key themes

1. **The need for a long-term perspective**
   - Services should provide support through crises and periods of wellness
   - Clinicians' expectations of "recovery" different to service users

2. **Need for holistic and individualised care**
   - Holistic approaches to care *(addressing mental/physical health, social, economic, environmental and practical needs)*
   - Individualised care *(care that is responsive to individual's needs at that time)*
   - Collaborative care planning *(joint care planning, assessments grounded in the experiences of individuals, asking people what strategies/resources they use to keep well)*
   - Trauma-informed care

3. Interpersonal connection/therapeutic relationships

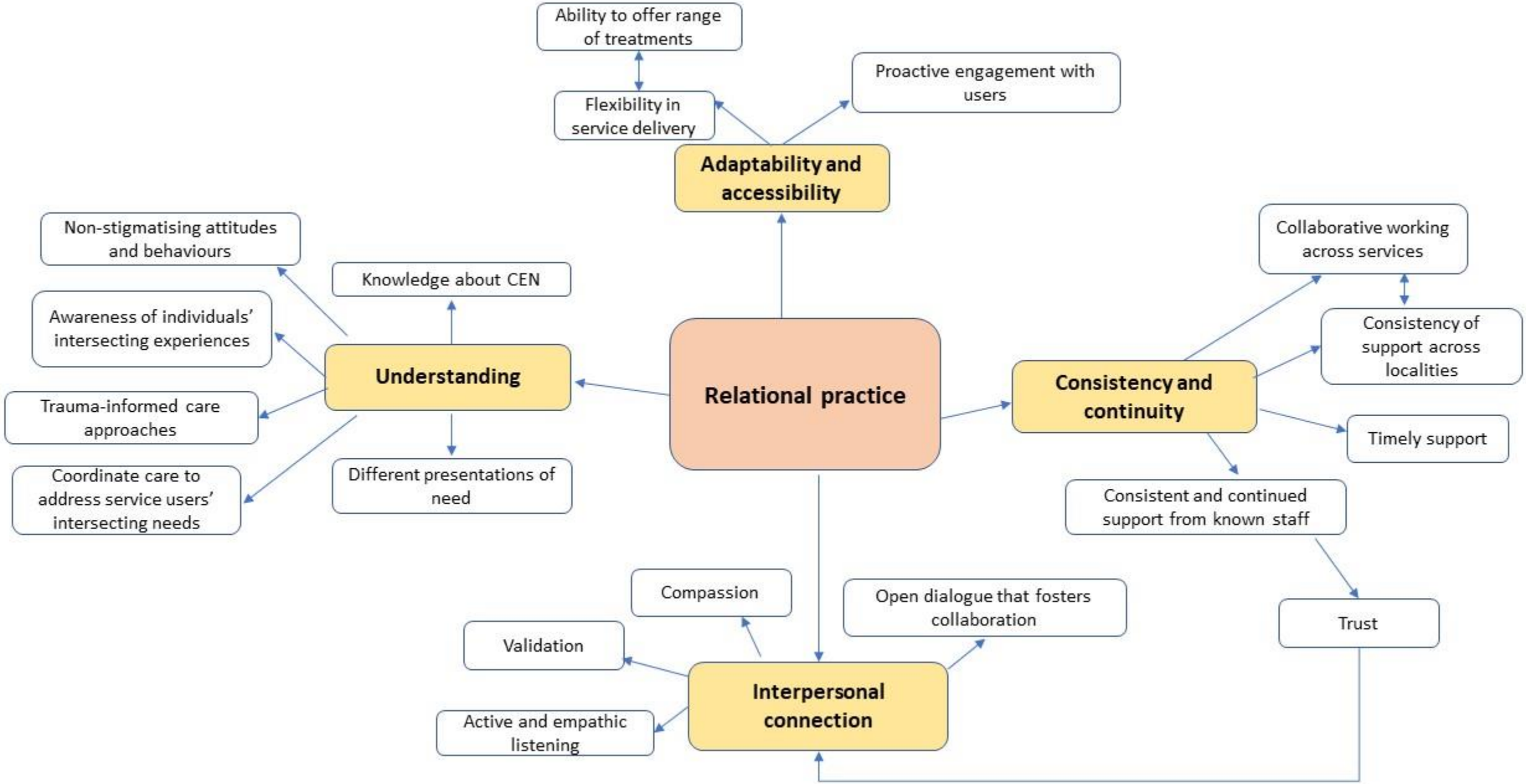
- Good client-staff relationships *(staff that are warm, validating, non-judgemental, compassionate)*
- Staff need to be flexible in responding to changing needs of service users *(understanding capabilities and limits of users)* and establish clear boundaries
- Careful management of staff changes and consideration around discharge

4. Stigma of “personality disorder” diagnosis

- Stigma of label leads to service users being treated differently across a range of services
- Conceptualisation of mental distress by community services *(services underestimating the level of peoples’ distress, dismissing requests for help)*

5. Variations in accessibility and quality of community services for people with complex emotional needs

- Different service provision *(accessibility and quality)* depending on locality/service type
- Disjointed services
- Need for timely support *(to prevent mental health deterioration)*
- High thresholds for service use leads to exclusion


Ability to offer range of treatments
Flexibility in service delivery
Proactive engagement with users
Adaptability and accessibility
Non-stigmatising attitudes and behaviours
Knowledge about CEN
Awareness of individuals' intersecting experiences
Understanding
Trauma-informed care approaches
Coordinate care to address service users' intersecting needs
Different presentations of need
Relational practice
Collaborative working across services
Consistency of support across localities
Consistency and continuity
Timely support
Consistent and continued support from known staff
Trust
Compassion
Open dialogue that fosters collaboration
Validation
Interpersonal connection
Active and empathic listening

Staff views on good community care for people with complex emotional needs and how it could be achieved

A qualitative study and meta-synthesis

Systematic review and meta-synthesis

Aim

- To explore the perspectives of mental health staff concerning good quality care for people with CEN in community settings, including both specialist and generic settings to identify the potential (or existing) facilitators and barriers to providing this care.

Design

- Systematic review and meta-synthesis of international literature of clinician perspectives on what constitutes good practice in community mental health services for people with complex emotional needs published since 2003.
- 29 papers including over 550 clinicians from a range of settings.
- Half from UK, others mostly from elsewhere in Europe, Australia, or USA.

Qualitative study

Aim

- To explore the perspectives of mental health staff concerning good quality care for people with CEN in community settings, including both specialist and generic settings to identify the potential (or existing) facilitators and barriers to providing this care.

Design

- Focus groups and 1:1 interviews with 50 staff across England who were/had worked in specialist ‘personality disorder’ services or pathways, and staff working in non-specialist services who had experience of supporting/promoting the needs of people with complex emotional needs related to 'personality disorders’.
- 21 participants worked in a specialist CEN or “personality disorder” service, 29 identified worked in generic community mental health services.
- 32 participants worked in NHS services (n=32), 13 in third sector, 5 in local authority social care settings.

Key findings

1. Defining best practice care

- Patient centred-care
- Focus on relational care and the therapeutic relationship - clinicians negotiate a balance between connection and distance.

✓ *Invest into engagement, develop partnership, and improve clinician attitudes and therapeutic optimism through training and supervision alongside support from services*

Staff qualities required to provide best practice care
• Empathy and compassion • Skill • Authenticity • Flexibility • Supportive • Communicative

2. Facilitating best practice

- Acknowledge and address heterogeneity of needs
- Plan for discharge carefully and collaboratively
- Provide flexibility and offer diverse range of psychological and pragmatic support options delivered with structure and consistency at individual level
- Consider the balance in the needs of service users, clinicians, and service

✓ *Support clinicians through team working, informal support between colleagues, reflective practice, good quality supervision that addresses emotional needs, and continued training.*

✓ *Range of clinical backgrounds offers alternative perspectives and solutions for overarching aims*

✓ *Facilitate inter-agency working through effective working relationships, joint agency training, clearly assigned responsibilities, and overcoming service barriers*

Elements needed for a best practice service

- **Consistency**
- **Inclusivity**
- **Person centred**
- **Timely and available long term and in times of crisis**
- **Flexible**
- **Collaborative across services and sectors**
- **Evidence based**
- **Coproduced**
- **Acknowledging complexity**

3. Barriers to best practice

- Access and availability.
  - Issues of inclusion, referral pathways through and beyond stepped care system, long waiting times, regional variation, etc.
  - ✓ *Communicate throughout referral process, accept self-referrals, improve referral pathways through stepped care.*
  - ✓ *Provide high quality, holistic assessments considering social, psychological, physical needs even if unsuccessful referral.*

- Staff burnout, fear, and concerns about risk.

- Managing safety issues and crises.
  - Feelings of hopelessness and burnout
  - Appropriateness of out of hours support / clinicians being 'on call'
  - Chronic, recurrent and predictable risk presentations (rather than acute)
  - Resources and support for risk management
  - ✓ *Proactive, collaborative plans, outline response parameters, share responsibility with service user and clinical team (not risk-averse, reactive)*

4. Addressing systemic challenges

- Stigmatising cultures: the use and misuse of diagnosis
  - Common language among clinicians
  - Validity, stigma, limited use for accessing treatment and information
  - Alternative diagnoses, euphemisms and descriptors used instead
  - ✓ *Co-produced training and service design*
  - ✓ *Leadership and role modelling across services*
  - ✓ *Policy change*

- Resources and Funding

Health economic evaluation of care for people with complex emotional needs

Aims and methods

- Systematic review of economic evaluations of interventions for people with complex emotional needs.

- Analysis of routine data from secondary mental health services to understand service use and costs related to complex emotional needs and to identify cost predictors.

- Modelling the cost-effectiveness of innovative services.

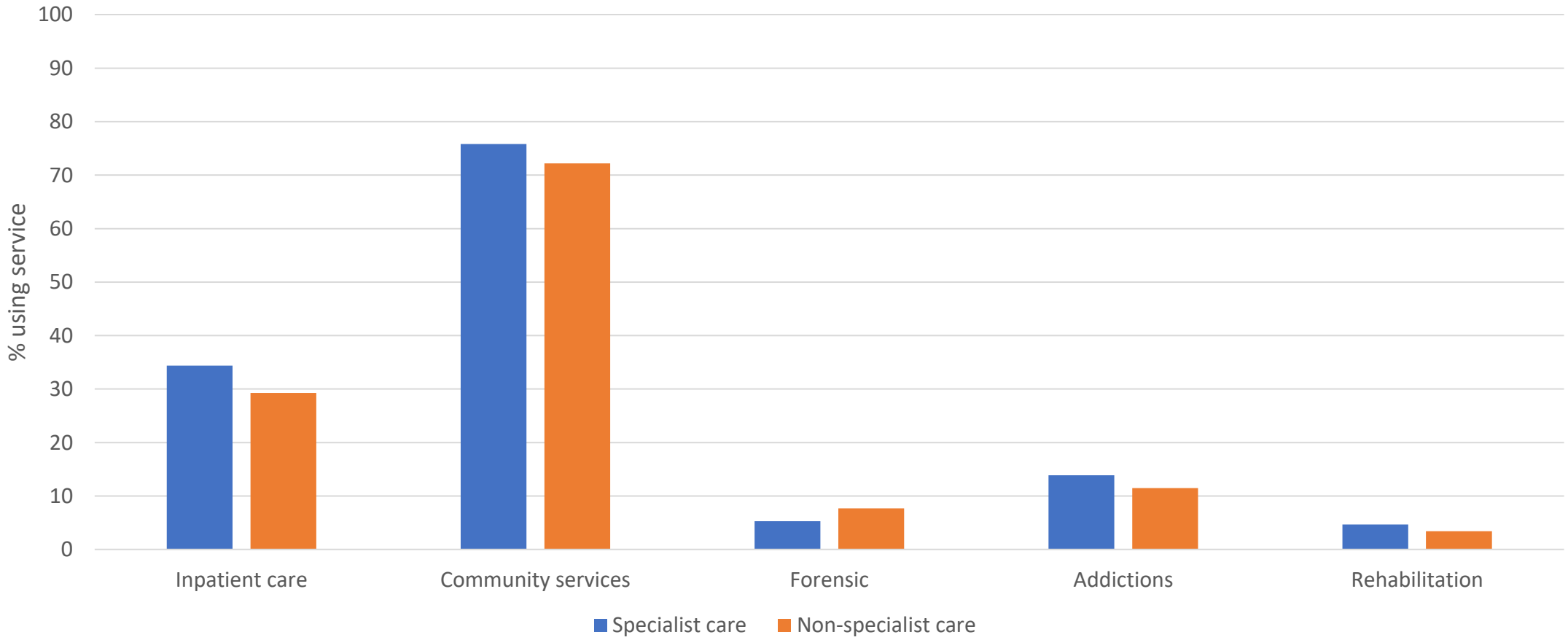
Systematic review – contributing evidence

- 18 studies of 19 interventions:
  - DBT (n = 3);
  - CBT (n = 3);
  - Stepped Care (n = 3);
  - Setting (n = 2);
  - Nidotherapy (n = 2);
  - Schema-Therapy (n = 2);
  - Joint Crisis Plans (n = 1);
  - Psychoeducation with Problem Solving (n = 1);
  - Clarification Oriented Psychotherapy (n = 1);
  - Mentalization-Based Treatment (n = 1).
- Studies from UK, Netherlands, Australia, and Norway.

Systematic review – key findings

- Limited robust evidence to support the cost-effectiveness of any particular therapeutic approach
- Small sample sizes across studies
- No interventions appeared to be co-produced with service users
- Outcome measures in many studies (e.g. EQ-5D) very limited
  Strongest evidence (from 3 studies) was for dialectical behavioural therapy
- Some evidence for cost-effectiveness of scheme-focussed therapy, joint crisis plans, stepped care, nidotherapy, psychoeducation with problem solving, and MACT

Routine data analysis: use of services post-diagnosis

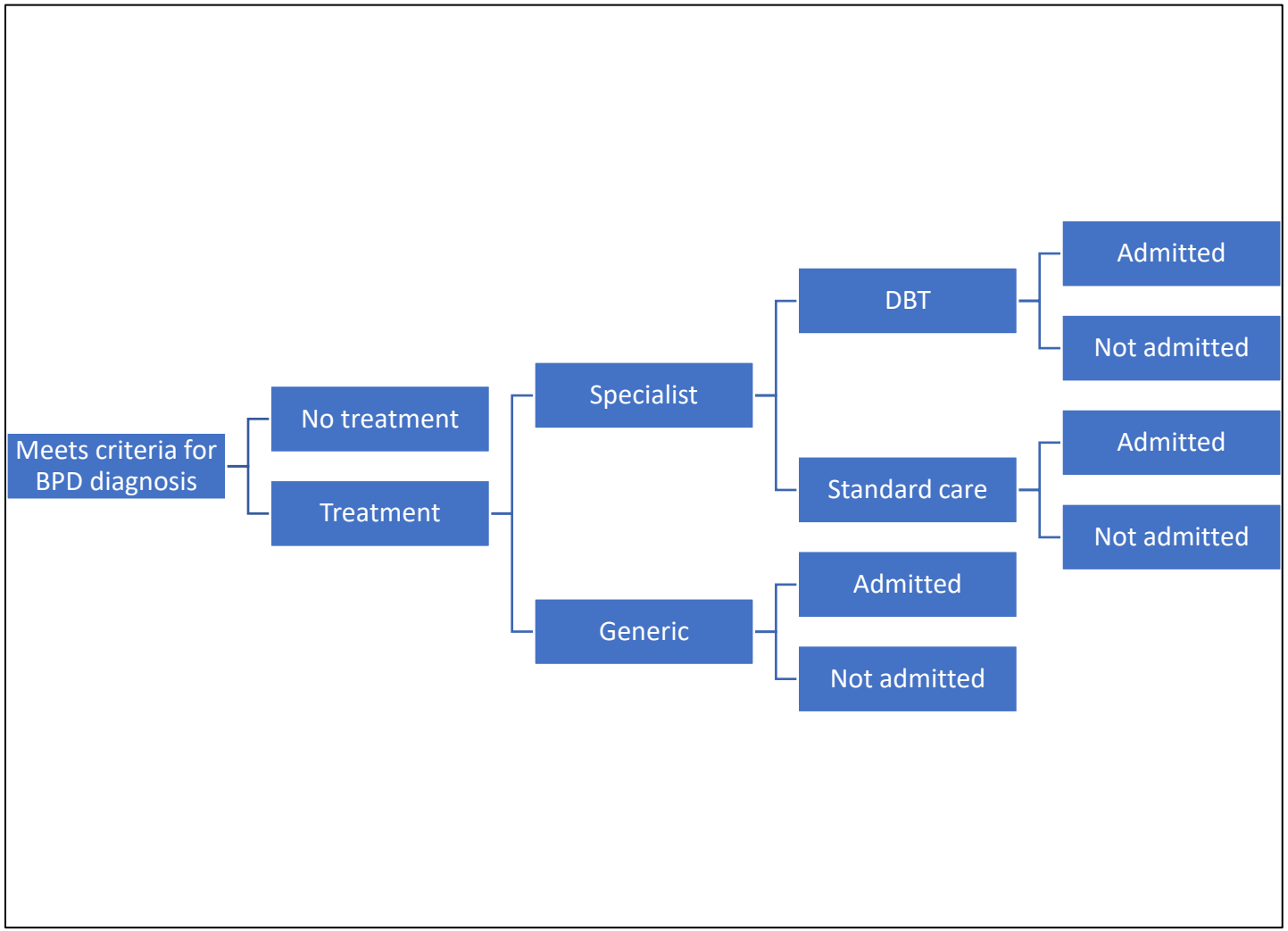


Predictors of post-diagnosis service costs

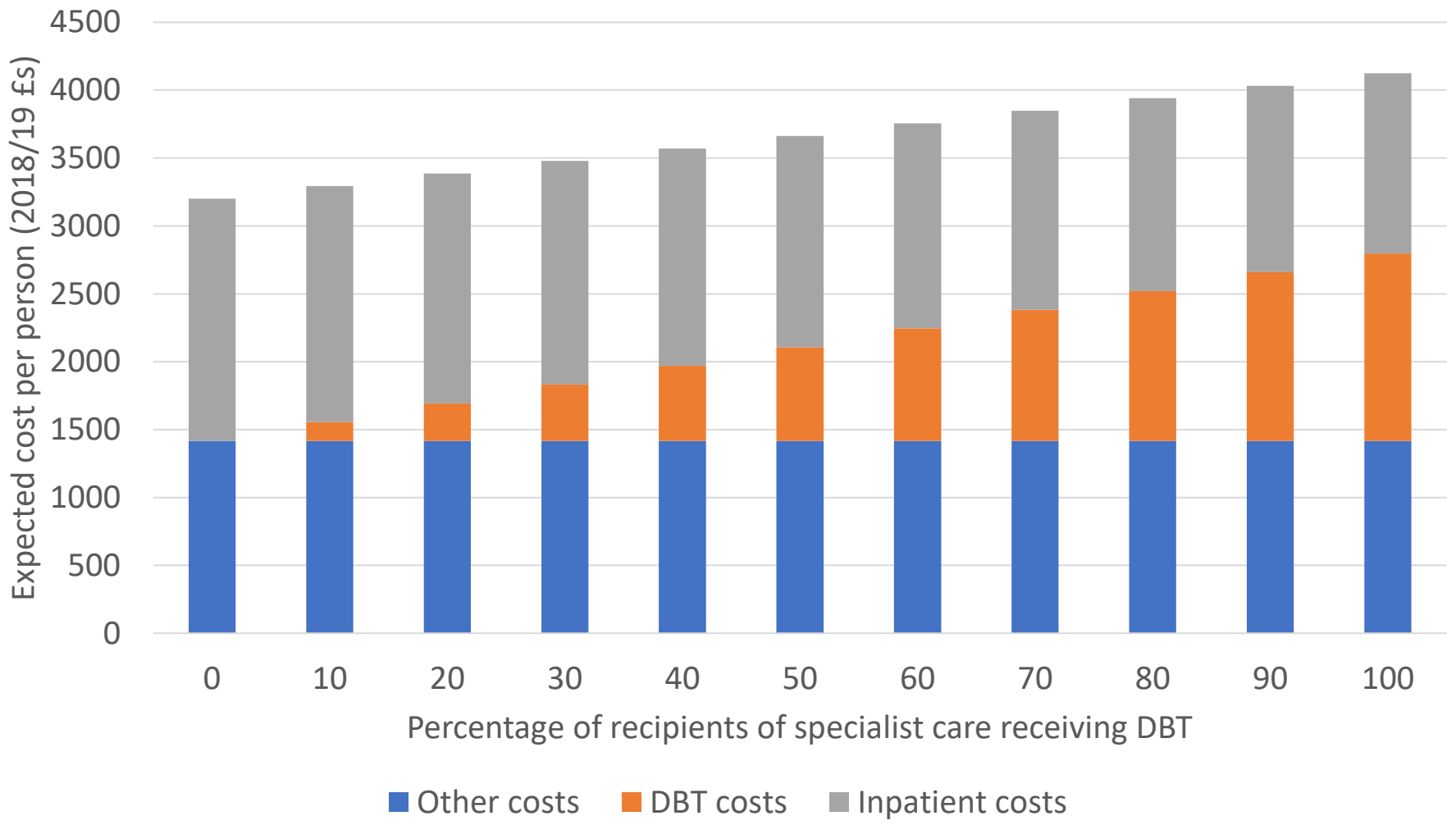
- Days in post-diagnosis period
- Previous costs
- Number of specialist care contacts
- Residence outside of area
- Diagnosed learning disability
- SMI diagnosis
- Addiction

Modelling component

- Uses decision modelling
- Model can assess impact of various interventions
- Dialectical behaviour therapy used as exemplar
- Focus on therapy costs and inpatient costs



Key findings



Implications and further work

- Published literature does not provide clear evidence about cost-effectiveness of support for people with complex emotional needs
- Modest evidence in favour of DBT
- Analysis of routine data suggests little difference in costs for those in contact with specialist services
- Modelling work to be enhanced by use of data from early implementor sites

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Time for a cup of tea….
Back at 3pm!