Peer support for intimate relationships after stroke:

initial findings to inform a co-designed digital self-management programme

Intimacy after stroke

- ABI ⇔ Stroke: overlapping long term consequences

- Mental health ⇔ sexual wellbeing

- Rehabilitation in UK is inconsistent and inadequate
  - Current issue on government and funder agendas
  - Policy review pending

- Evidence for **peer-supported** self-management after stroke, but

Is peer support appropriate for issues relating to sexual wellbeing and intimacy?
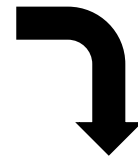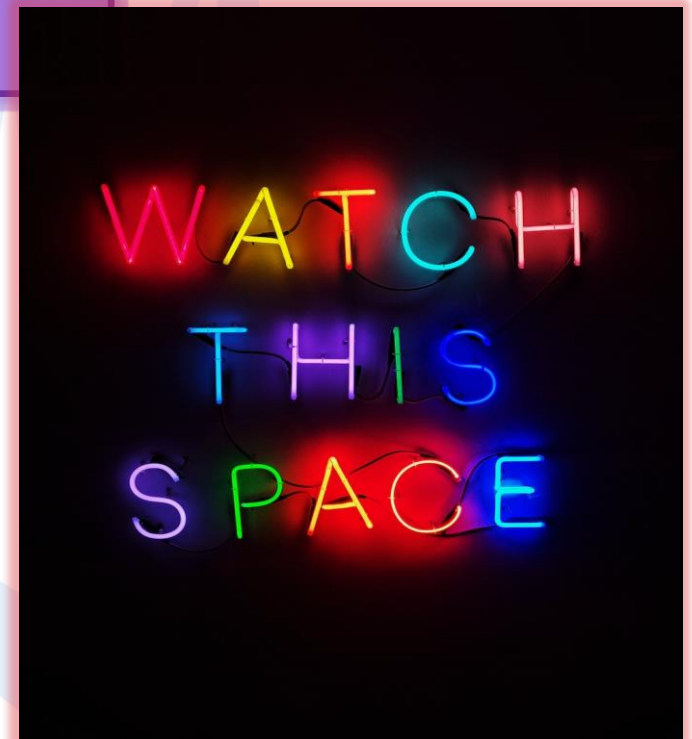
A brief history of HOPE
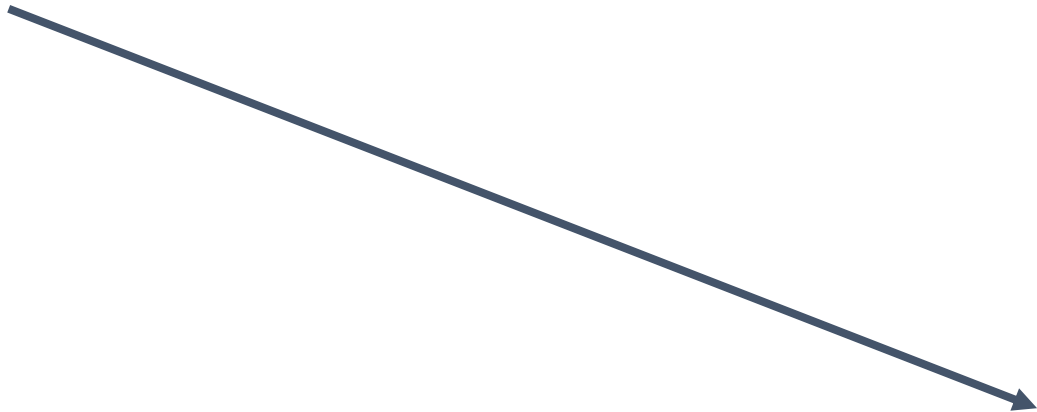
PHASE 1:

"Co-design, refine & optimise"

- Generate new content
  - (HOPE4ABI)
- Repurpose existing content
  - (from The Hope Programme©)

- Iterative user-testing
  - Patients and professionals

PHASE 2:

Randomised controlled trial (RCT)

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WATCH THIS SPACE

Patient-led research

Experience-Based Co-Design

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	Activity		Purpose	EBCD Stage
	Professionals	Patients		**Stage 1:** set up; recruitment
Step 1: Information gathering	Workshop	Workshop	Identifying unmet needs	**Stage 2 & 3a:** gathering experiences
Collaborative prioritisation	[Review]		Mapping needs to intervention content	**Stage 3b:** developing summary
	Workshop	Workshop	Present summary and refine priorities **within** each group	**Stage 4a:** within-group feedback and identification of HOPE4ABI content
	Combined prioritisation activities		Summarise and refine priorities **across** groups	**Stage 4b:** Confirm collaborative priorities; establish co-design groups
Step 2: Codesign	Co-design workshops		Developing content for HOPE4ABI intervention	**Stage 5:** Patients co-design new modules
Testing	Iterative user-testing		'Think Aloud' technique and narrative interviews to refine and optimise HOPE4ABI	**Stage 6:** Patient testing of one new & one repurposed module

Workshop Design & Aims

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Lived experience

+

Professionals

Key questions

Issues/Barriers?

Useful content?

Presentation?

Initial findings

Relationship dynamics change
Masking problems
Role changes
Acceptance
Peer-support
Nurturing relationship
Feeling safe talking about sex
Loss of confidence
Relationships pre/post injury
Emasculation   Misdiagnosis
Lack of confidence
Grieving
Inadequacy   Isolation   Self-esteem
Loneliness   Tolerance
NHS barriers   Relationship loss
Managing ABI is tiring
Patience   Gratitude
Normalisation
Reliance on partner
Sexual preferences
Understanding
Personality changes

Themes & Content

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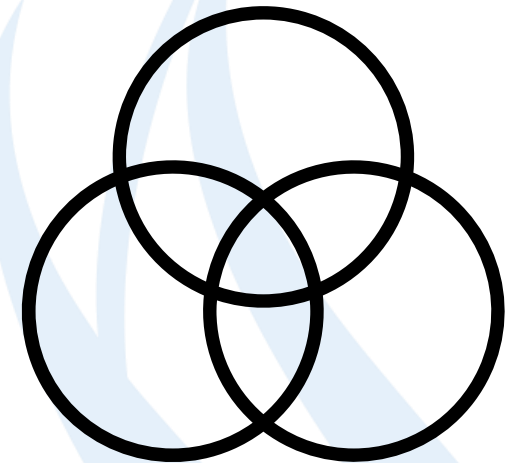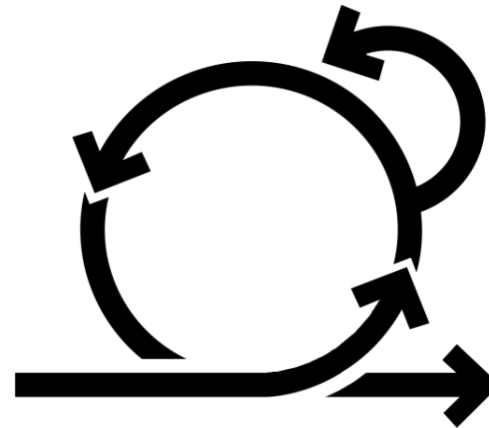
Impact of ABI
- Body
- Mind
- Practical
- Relationships

Coping Strategies
- External support
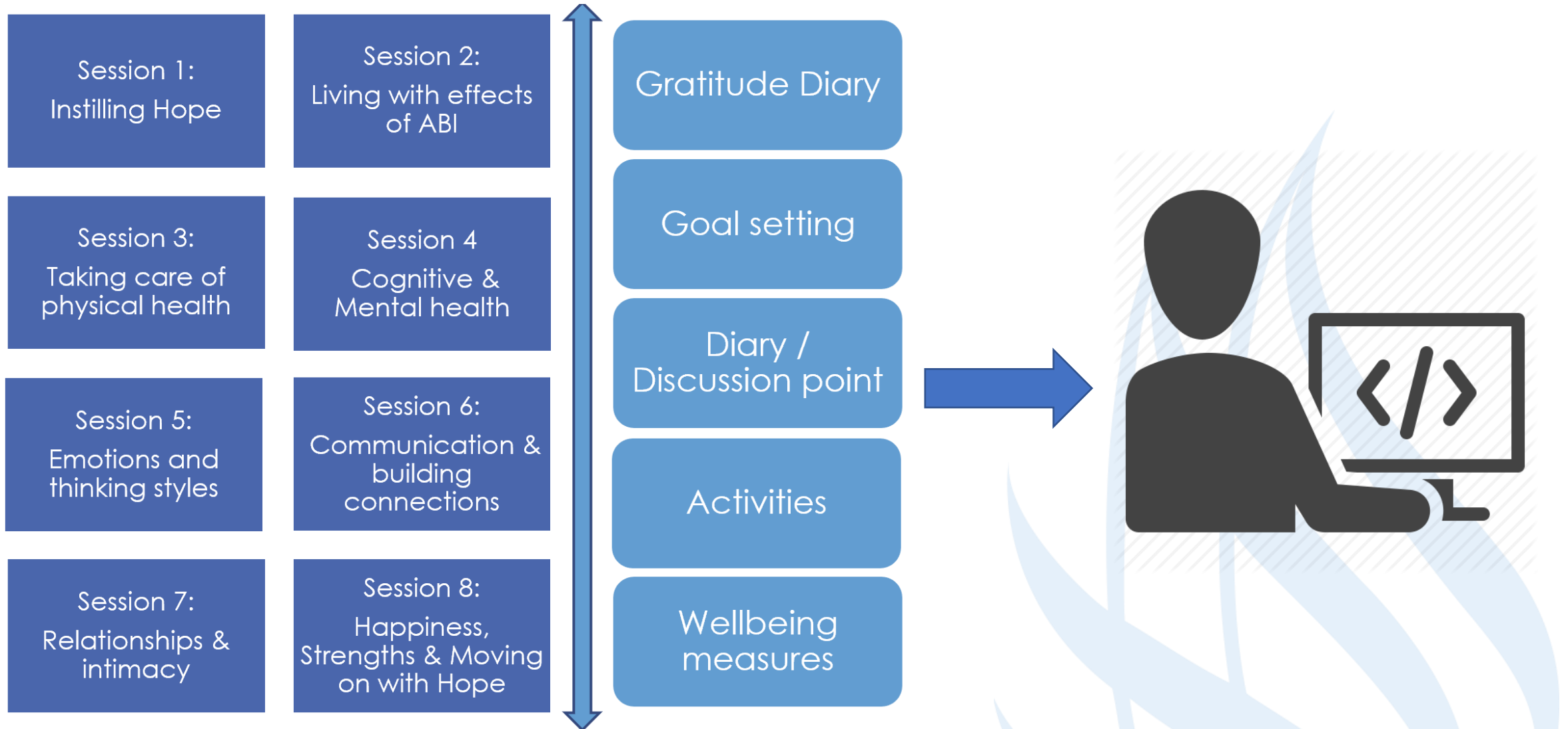- Internal strategies
- Skills

Delivering HOPE4ABI
- Activities
- Pacing
- Suitability
- Presentation
- Accessibility

Language of sex & intimacy

Value of peer support

Perspectives on self management

Content Mapping – tbc …

Thank you!

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