"T'aint what you do…it's the way that you do it."

Principles of supporting self-management

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So what?

- 1.1 million stroke survivors in the UK (Stroke Association, 2013)

- Issues: abandoned, no information, no practical advice, increased stress and anxiety, lack of emotional support (Stroke Association, 2013)

- Priority for NHS England and NHS Scotland (Department of Health, 2007, Scottish Government, 2014)

- 3rd sector organisations, including Chest, Heart and Stroke Scotland & The Stroke Association

Challenges remain…

- What does stroke self-management mean to stroke survivors, carers & practitioners?

- What are practitioner's experiences of delivering self-management support?

- What specific types of self-management support do people want and when do they want it?

- Priorities and outcomes – what matters to me?

- Focus on delivering "the service" – constrains broad approaches to supporting self-management?

- How can we best translate research evidence on self-management support into practice and what contexts support this?

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Phase 1 Development of Intervention

- Systematic literature review
- Semi-structured interviews (stroke survivors, n=20)
- Focus groups/telephone interviews (stroke nurses, n=11)

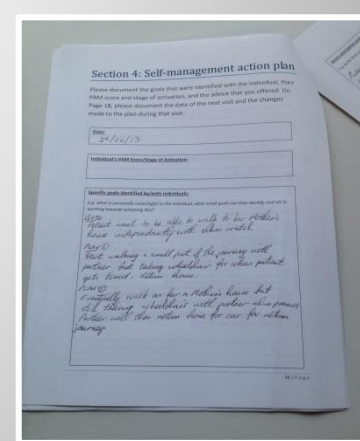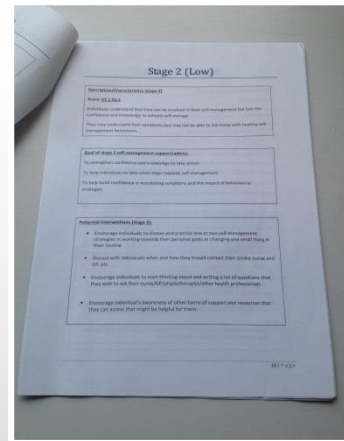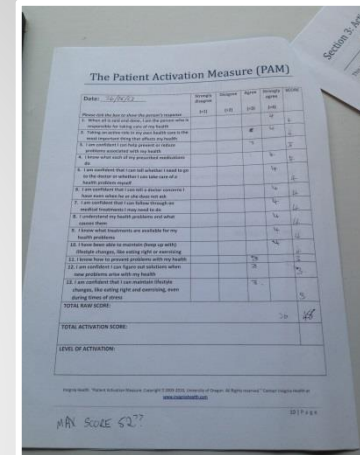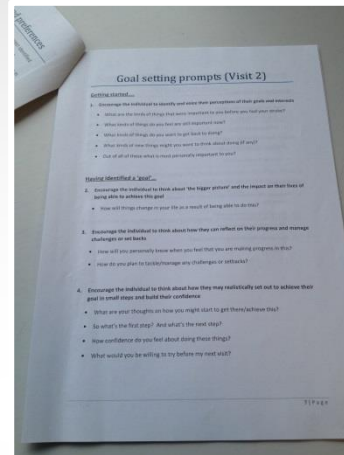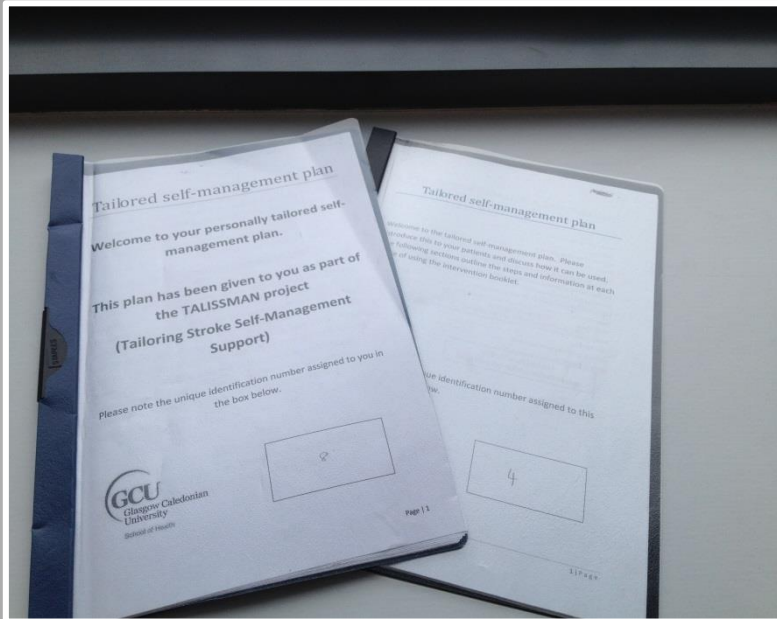**Phase 2 Implementation & Evaluation of Intervention**

- Pilot test of the intervention
- Qualitative evaluation (stroke survivors n=6, stroke nurses n=5)

Theoretical underpinning

- Patient Activation Theory (Hibbard and Cunningham, 2008)
- Self-management, decision making and tailoring of interventions

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Understanding self-management

V2: I think it's about them [patients] taking control after they have had their stroke, it's about them controlling their life rather than us [nurses] going in and doing things for them, we can give them all the information but they've got to be willing to take this control and move a step further….[pause]

V1:	But the other thing is though is the fact that would that, you know, that [the intervention] ultimately did in the end make that lady self-manage but *you* still had to facilitate it all.

V3:	We did

V1:	So *we* are still kind of, you know…

V3:	She did self-manage because she told me what she wanted to do and then she went and done it

V1:	But *you* facilitated it

Language of self-management

V2:	That other lady...she's been goal setting with her husband because she has been walking to a bench and then stopping and then two benches and then back. She didn't see that as goal setting as her goal setting was to get a shower and get up her stair and I says "but you're actually doing that now".

 V3:	You're just verbalising it as goal setting.

 V2:	That lady was goal setting, her husband and her were motivated enough because she just didn't want to be in that wheelchair

V1:	I think the word goal is wrong.

V2: Patients aren't their not aware of anybody talking about goals apart from Celtic and Rangers or whatever [laughter] you know so it's not a word in their vocabulary [agreement].

Recording self-management activities

V1:   But probably you would have gone through the same process but just recorded it in your notes whereas you're recording it in a goal format really.

LK: How different was it?

V1:   Hugely different [all voice agreement].

V4:   I suppose we *are* doing goal setting just now anyway we are just doing it *differently*. We are not doing the recording stage of it…our patients still have goals they say like "this is what I want to do" and we are going to help them through that process. We are just not *formally* writing it.

V1:   And recording it.

V3:   Well I suppose with like the girl I have done it with she wouldn't have verbalised that without me asking 'what's that goal that you want to be achieving?...she said "It gives you a focus… to know that's there and I've filled this in and I know it's there and we've talked about it".

Implementing self-management in practice

V4:   Its swings and roundabouts, you know, the next three months might be really, really, easy, you just don't know what you're going to get until you get there.

LK: Yeah, yeah…

V4:   I certainly had to make, to achieve what I achieved it had to be done over three visits.

V3:   And it's absolutely time.

V1:   And it's adding onto your…[workload]

V3:   And that's _not_ what we would normally do.

V1:   And it's trebling the workload!!

What does this tell us?

- Operational obstacles e.g. consultation times staff shortages, organisational structures

- Contexts and subtleties shaping interpretations and delivery of self-management support

- Recognition of diversity in practice of supporting self-management and diversity of interpretations

- Relationships and communication are key
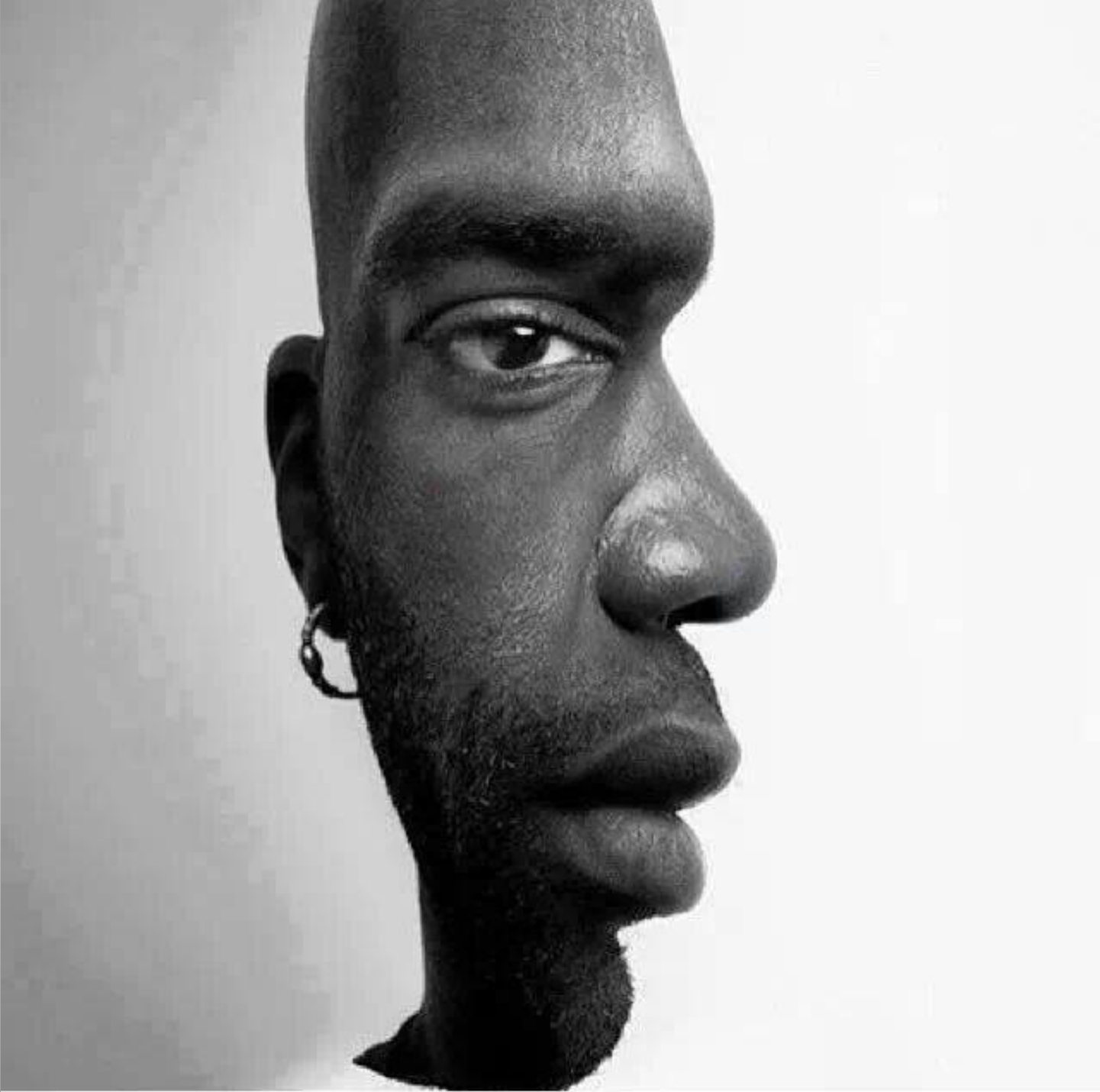
A question of purpose?

Narrow interpretation:

- Support is typically geared to encourage them to adopt the condition monitoring, treatment and/or lifestyle behaviour regimes that in general terms contribute to disease control (and that may previously have been undertaken by practitioners

- Self-management = compliance

- Culture of risk reduction and patient safety

- Restricted scope for engagement in self-management support

- Practitioners in control?

A question of purpose?

Broader interpretation:

- Support orientated towards helping people to manage or live well with their conditions
- Guided by people's own views of what is important in their lives and that they can shape their own lives rather than have them shaped by others
- Recognize progress in a number of domains rather than just biomedical indicators
- Approaches involve practitioners taking time to listen and get to know the person and what's important to
- Collaborative working to address priorities and goals
- Professional–patient relationship is constitutive of the support that practitioners offer.

How can we support stroke self-management?

Transferable, flexible principles...

1. Understand and acknowledge individuals' perceptions and expectations around self-management and ground the delivery of self-management support within these
2. Conduct a brief targeted assessment, which along with assessing clinical severity and functional status, should include the individual's self-management priorities, preferences, abilities and support needs, and barriers and enablers to their self-management
3. Elicit patient-initiated goals through the use of approaches such as motivational interviewing, guided by the principles of the client, rather than the counsellor, evoking and voicing their motivations and arguments for change
4. Enable and encourage individuals themselves to identify and articulate 'goals' that are personally meaningful to them, framing them in a manner that they will identify with and respond to, and work in partnership to devise a way in which they might start to work towards these
5. Document and record 'goals' and 'self-management action plans' in a systematic manner that will help to guide and structure the delivery of self-management support
6. Ensure that self-management support 'fits' with practitioners' daily clinical practice; the principles of person-centred self-management support should underpin care delivery rather than being another 'thing' which results in the need for additional time, visits or added pressure on practitioners.
7. Ensure that the philosophy of self-management and the provision of self-management support is part of a whole system change which values self-management and supports practitioners to deliver stroke self-management support in a timely and person-centred manner, rather than being an individualistic, opportunistic and ad hoc approach
8. Ensure that these principles underpin all aspects of care delivery which will help 'nudge' towards a culture of person-centred interactions and person-centred self-management

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