TITLE

On the character and production of ‘active participation’ in neuro-rehabilitation: an Actor-Network perspective
Abstract

The importance of patients' active involvement in neuro-rehabilitation after acquired brain injury has been consistently emphasised in recent years. However, most approaches fail to show how 'active participation' is practically enacted, focusing on individualised explanations of patient choice and behaviours, or notions of inherent patient traits. Using Actor Network Theory (ANT) as a sensitising concept, we investigated neuro-rehabilitation practices, asking how participation is shaped through biological and socio-material specificities, how rights to knowledge and expertise are constructed, and how a body acclimatises and adjusts within an order of participation and transformation. We analysed video-recorded fieldwork extracts, examining the work of adjusting, testing and transforming; the construction of competence and incompetence; and material and social processes involved in the division of the body and its re-composition. Our findings show how an ANT-sensitised approach provides a critical understanding and context-specific characterisation of 'active participation', produced through the association of heterogeneous actors at any one time. Such specificity and the distribution of work suggest that efforts to account for optimum therapy 'dosages', and clinical attention to establishing individually-located levels of 'self-efficacy' or 'motivation' are misdirected. The performance of 'active participation', rather, should be re-imagined as a product of diverse, mutually attuned entities.

Keywords:

Actor Network Theory (ANT); neuro-rehabilitation; active participation; therapy
Introduction

Neuro-rehabilitation is defined within physical and medical rehabilitation as a co-ordinated process of assessment and intervention, in which patients with acquired neurological conditions caused by head-injury or stroke for example are enabled to (re)acquire skills relevant to their daily lives (Meyer et al. 2011; Gutenbrunner et al. 2006). Learning for recovery or adaptation is integral to modern concepts of neuro-rehabilitation (Gutenbrunner et al. 2006), with minimum therapy dosage (Intercollegiate Working Party 2016; Lohse et al. 2014) and early active involvement of patients highly recommended in the many guideline and standards documents accompanying initiatives to improve quality (e.g. Meyer et al. 2011; Intercollegiate Working Party 2016; National Institute for Health and Clinical Excellence [NICE] 2013). However, as a recent report on the state of involvement in health and care puts it: “we lack clarity about the business of involving people in health” (Foot et al. 2014: 6).

‘Active participation’ has served as convenient shorthand for practitioners and researchers of neuro-rehabilitation practice to frame patient involvement in particular ways. Studies of patient choice (shared decision-making; goal setting), and behaviours (compliance and adherence; engagement and participation), or clinician behaviours (power; control and patient education) have predominantly used phenomenological, behavioural and psychological approaches to focus on individualised explanations. Patient perspectives have been valued as an object of study in themselves (e.g. Schoeb and Bürge 2012; Proot et al. 2007), providing an alternative to bio-medical knowledge, with studies often linked to initiatives intended to improve the quality of treatment practices (Pols 2005). Degree of active involvement has been related to levels of patient motivation, often conceptualised as an inherent trait (Maclean and Pound 2000). Discrepancies between individual goals
and performance (Brands et al. 2012), and belief in personal capability to perform an activity (‘self-efficacy’) (Bandura 1997; Dixon et al. 2007) are both thought to influence motivation and action. However, environmental factors, such as professional attitudes (Maclean and Pound 2000), communication practices (Parry 2004a,b), overprotection by family or staff, and the hospital milieu (Proot et al. 2007; Maclean et al. 2002) have all been identified as impacting on patient experiences of and attitudes towards rehabilitation.

With the exception of ethnomethodologically-informed studies of neuro-rehabilitation (e.g. Barnard et al. 2010; Parry 2009; 2004a,b; Martin 2009; Struhkamp et al. 2009) most approaches fail to show how ‘active participation’ is practically enacted. We question any assumption that ‘active participation’ can be framed in ways which make actors’ entanglements with other networks invisible (see Winthereik and Langstrup 2010 for a discussion of Michel Callon’s notions of framing and overflowing), essentially the responsibility of or simply intrinsic to individuals (patients or practitioners). Medical neuro-rehabilitation may focus on the condition of individualised, discrete and bounded bodies (Moser 2009; Foucault 1976) but its practice is messy, embedded in buildings and spaces, where individuals and objects enter into interaction for certain purposes, acting with and for others, influencing and influenced, forming temporary and contingent associations. As such, we argue for a shift in attention to the relational dynamics of social and material components of neuro-rehabilitation (see Moreira 2004). The concepts and tools of Actor-Network theory are especially relevant for us here in formulating and addressing these questions.
Actor-Network theory

We do not attempt to review the extensive literature on Actor-Network theory (ANT) but focus on those key aspects we have drawn on for a study to be discussed here, of the social and physical in constituting participation in neuro-rehabilitation. Mol (2010) emphasises how ANT-type work deploys a repertoire of sensitising terms and ways of asking questions, using techniques “for turning issues inside out or upside down” (2010: 261), attuning differently to reality so to describe (but not to explain) effects. A key principle of ANT is that of encompassing heterogeneity. Actors, also called ‘entities’, both human and non-human, form networks through associations with other actors enrolled or translated into such networks, which hang together through hard work. The actors involved afford each other their existence and capabilities, and may mutually adjust themselves to one another co-ordinating, tinkering, doctoring, and attuning (Mol 2010: 262-265). We are specifically interested in the effects of this ordering in neuro-rehabilitation practice, how networks come together, hold and may be sustained (Strathern 1996), but also how they co-exist and fall apart (Mol 2010).

Neuro-rehabilitation work entailed in ‘getting better’ or ‘returning to functional activities’ involves interventions, where ‘recovery’ will assume a return to a bodily state and behaviours present before neuronal damage, while ‘adaptations’ or ‘compensatory strategies’ are those that patients develop (Levin et al. 2009). Actions entailed in these interventions, distributed between humans and non-humans, are made possible through the emergent effects of actor-networks, a set of specificities which change over time and distance, with moment-by-moment adjustments to an array of heterogeneous materials (Law and Moser 2011). Various technologies are enacted throughout the work of rehabilitation. Technologies designated as ‘hard’ include high- and low-tech objects and geographies; ‘soft’ technologies include
written texts, systems and schema. In the settings which we studied, technologies comprise spatial dimensions (corridors; distances between objects such as bed and commode), which may be enrolled or adjusted by therapists and patients; and diverse objects. Some objects must be deployed, applied or secured in particular, protocolised ways, already embodying the “inscription of builders and users” in their mechanisms (Latour 1992: 236). These could be: plinths; parallel bars; walking or mobility aids; strapping; ankle-foot orthoses / splints; or ingested products (thickener for drinks). These are designed to keep patients safe, prevent increased tone or pain and facilitate the body’s (re)learning. Other objects such as machines that enable repetitive practice (static bicycles; running / walking machines; robots; software programmes) may substitute for easily tired, bored, or unreliable people, as a “delegated nonhuman character” (Latour 1992: 231). Words are also actors and are key to the rehabilitation of speech, language or cognition, where their physical or symbolic properties are deployed (see Law and Moser 2011). Then there are ‘everyday objects’, enrolled by users for particular purposes as with beanbags (sliding across the top of a table); a trouser pocket (to support and keep safe a flaccid upper limb); a (recipe) book (to structure preparations for a meal to be planned and cooked); a whiteboard or flipchart (to record and share memories, thoughts, experiences amongst members of a group of patients working on ‘living with’ aphasia). There are objects which themselves play roles, taking the part of everyday objects such as clothes pegs or keys and coins, as when cones of varying dimensions or pegs in a board are deployed in exercises for strength and dexterity needed for everyday actions such as hanging out washing or reaching for a carton of milk. ‘Soft technologies’ (texts, systems and schema) are enacted, reported on or seen to be discussed (protocols; assessments; guidelines; academic theories; rehabilitation and safety procedures; risk assessments; incident reporting).
To examine ‘active participation’ within neuro-rehabilitation, we ask how such participation is shaped through biological and socio-material specificities, which change over time; how rights to knowledge and expertise are acquired, displayed, constructed and contested; and how a body acclimatises and adjusts to division and recomposition within an order of participation and transformation. To explore these questions we will work through empirical examples from fieldwork for a study of neuro-rehabilitation practice in the UK. We now go on to set out methods of data collection before presenting selected cases.

Methods
We have re-examined data from two UK studies conducted between 2001 and 2008, both focussing on neuro-rehabilitation for people with acquired neurological impairments. Each gained Ethical and Research Governance approvals (Ethics refs: 2001/015; 06/Q0101/160). Data collection was undertaken in a variety of settings: in- and out-patient stroke rehabilitation, Medicine for the Elderly, specialist neuro-rehabilitation and one residential home. We sought permission to approach staff, patients and relatives from the relevant organisations, and obtained written consent from all participants before collecting data. To study rehabilitation as day-to-day practice we carried out video-recorded therapy-focused observations on wards, in corridors, therapy gyms, consulting rooms, and residents’ / patients’ rooms. Video was used to record participants’ talk and action, and, importantly for the ANT-informed approach being taken, to detail spaces, objects and activities to make them available for repeated scrutiny (Heath and Hindmarsh 2002). We examined patient records for information on the nature of patient impairments and their medical and therapy treatments. Settings, participants and a brief summary of activities are set out in Table 1.
These data constitute a diverse range of participants, activity types and locations. For this paper and to address our questions, we have selected extracts from four different sessions involving three patients, their therapists, therapy assistants or student therapists (all given pseudonyms – see Table 1). The analytic narrative developed is set out in three sections. In the first, we address the collective work entailed in adjusting, testing and transforming as a patient learns to control her body’s balance and regain stability. In the second, we explore how a patient and her therapists engaged in rehabilitation lay claim to expertise and negotiate rights to knowledge and competence. Finally, we examine how professional, material and social processes in rehabilitation may divide the body, and how a patient may then work towards its re-composition.

**Findings**

*Tinkering, transforming and learning*

Betty is in her thirties, with a young family. She has been an in-patient in the specialist centre for three weeks now. Her spinal cord was damaged during surgery, leaving her with severe weakness and increased muscle tone in her left arm, leg and trunk.

Betty cannot stand without help or walk and uses a powered wheelchair, which she controls with a joystick on the right, manoeuvring confidently into the therapy room today. For the physiotherapy work on balance and trunk control Betty has to shift safely from her wheelchair to a plinth, a type of
adjustable couch. Anne, the physiotherapist, has positioned herself in front of Betty, asking her to shuffle forward and “put her feet where they should be” before she stands, reassuring Betty that Kate, a student physiotherapist is behind her “just in case”. Betty pushes up and swivels across to sit on the plinth. Anne tells her: “that’s brilliant, not bad, not bad at all”.

So Betty and wheelchair, a collective producing agency, ability and mobility, are now parted. Betty is disabled, purposefully, to prepare her for body work, where disability is located “as a condition in and of the body” (Moser 2006: 378). As Moser (2009) observes, after an injury a person becomes disconnected from the practices and collectives before the event, while becoming part of new practices and collectives. Agency and competencies may be distributed away, but then return. Here, as Betty transfers from wheelchair to plinth, her agency and competence to be mobile are distributed away from her. But now a different set of specificities, a new collective of human and non-human actors evolves. With Betty seated on the plinth, therapist and helpers prepare her body so new associations and capabilities can form, mobilising a complex set of subjective capacities for action, consciousness, thinking and feeling, to contribute to her body’s healing (Moser 2006: 377).

Anne adjusts the plinth so Betty’s feet are squarely on the floor; Liv, a therapy assistant, Kate and Anne help Betty out of her T-shirt and take off her trainers; Liv removes the air-cast splint that has been supporting Betty’s left ankle; Anne asks Betty if she minds Anne rolling up her vest a little “so we can look at your tummy”, and then positions a tall mirror in front of Betty, who will use it to make adjustments to her posture and seating. Anne, now kneeling on the plinth behind Betty’s back takes stock of the situation:
“OK, not bad, good … you’re slightly back on this buttock (placing her hand on Betty’s left buttock), on your left side. Can you just shuffle that forward slightly (Betty adjusts) – good”. Betty is looking straight into the mirror and asks whether she is quite balanced. Anne thinks she is and they prepare for an exercise (to be repeated ten times). In this exercise, Betty must stretch out the right side of her trunk by reaching forward and up with her right arm to touch Liv’s raised hand, now standing in front of Betty. After her first attempt, Anne comments “that’s just a little too far” and Liv lowers her arm slightly and moves closer. Anne, who has placed her hand under Betty’s left buttock, is now observing Betty’s work. She asks Kate, positioned by Betty’s feet: “Are her feet staying on the floor there Kate?” When Kate reports that Betty’s left heel is “sneaking up a little bit”, Anne asks Betty to try and concentrate on the weight going through her left heel, while keeping both buttocks on the bed as she reaches up towards Liv’s hand.

Betty is making progress. After she has finished her stretches, Anne sums up: “That’s very good Betty, that’s nice and even, and you’re maintaining weight through this buttock, which you haven’t been doing. And it’s looking better from the point of view of this high tone that’s been here (rubbing her hand across the left side of Betty’s back) – it’s starting to dissipate a little bit.”

So the body-Betty learns, little-by-little, and the subject-Betty appreciates. Betty’s capacity to sense and act in ways designed to effect neural changes is made possible as Anne herself learns from Betty’s body, noticing and marking states and changes through touch and seeing. As in Winance’s (2006) study of testing and choosing a new wheelchair, there is a trying-out period, of making and unmaking connections, with actions decomposed and recomposed through material and
heterogeneous networks. But here subject-Betty is testing how body-Betty performs, enabled by this array of human and non-human actors, all coming together in specificities that shift, transform and produce stable associations, which will in time become learnt as automatic, unthinking performances. As actors come together, networks produce continuing efforts and effects: the plinth, set at the right height affords Betty the continued stability she needs to act; the mirror mobilises her capacity to monitor her position; the air cast, once removed produces a greater degree of agency in Betty sensing and adjusting her ankle’s position; as Anne provides verbal feedback and guidance alone, so must Betty attend more closely to her body sensations and effect control over her movements. So we are with Mol (2010: 264) in arguing that all associated (and dis-associated) actors are to be credited for the action involved in getting together and producing the effect – active participation – we can observe.

**Contesting competence**

Geraldine, who worked for many years as the manager of a care home is in her late sixties and recently had a stroke. She is widowed and lives alone in a flat not far from the hospital where she is an in-patient.

Liz (OT) and Hilary (PT) have brought Geraldine into the therapy gym in her wheelchair. Hilary explains that she and Liz want them all to look at things Geraldine will need to do in her kitchen at home. They have made a mock-up of her home kitchen to try and help them all, as Hilary puts it “to think about the kitchen assessment and all the little tasks involved in it, like keeping your balance, knowing where to place the walking frame”. “Is that OK?” Hilary asks. Geraldine nods briefly but immediately says: “There’s one thing (pointing),
that’s too high – I had everything lowered because I’m little”. It is apparent that Liz has already visited Geraldine’s flat because she remarks that she’s noticed some high cupboards in her kitchen; Geraldine counters that she keeps things in there that she’s not likely to use or very rarely needs. Geraldine is very specific in stating exactly how she wants Liz and Hilary to adjust the mocked-up shelves and their contents.

So knowledge of the body-in-context is a focus for those involved in making the adjustments necessary for precise and personalised rehabilitation here. Doing this requires self-awareness, active participation and collaboration between Geraldine and her therapists, in negotiating and establishing knowledge, rights to knowledge and expertise. Here self-awareness of ‘doing a body’ as it forms associations with diverse entities (cupboards, plates, freezers, cookers) not just in the present, but where it might be “when I go home”, highlights the interdependency of patient and therapist in undertaking the articulation work of rehabilitation (Strauss et al. 1985; Mol and Law 2004). But as we have seen elsewhere, patient-expressed choices or goals may be reformulated or refocused by therapy professionals to make them achievable or measurable, even when patients show resistance (Barnard et al. 2010; Parry 2004a; Talvitie and Reunanen 2002). Here, the future, unpredictable but perhaps imagined by Liz and Hilary is folded into the here-and-now, as these therapists take steps to make it relevant to present action (Struhkamp et al. 2009), as we now see.

Hilary and Liz have set themselves to explore how Geraldine will cope with filling a kettle to make tea, “just practising that reaching and filling”. Geraldine is quick to point out that she only puts just enough water in the kettle for one cup, so using less energy. Now Geraldine moves forward with her walking
frame, slow and unsteady. Liz and Hilary raise their arms protectively behind her as if anticipating a fall as Geraldine approaches the ‘sink’ and reaches across to the kettle. As she lifts it from its base, getting the feel of the weight, Liz urges her to think about what she is doing, and Hilary tells her to “take her time”. Liz comments: “something extra to think about in the kitchen with a frame is where you’re going to put the frame in order to reach things”. Now Geraldine counters: “everything will be put close, let me tell you”. She taps repeatedly on the ‘kitchen surface’ as she makes her point. Hilary joins in: “But Geraldine what we’re thinking is where are you going to put the frame?” “The frame is with me”, says Geraldine. Hilary and Liz are now standing either side of her as Liz offers: “Sometimes we recommend that if people want to get closer to a surface, we recommend that they put the frame, just as they get up to it to one side” as she mimes the action. Geraldine argues that she does not know what she is going to do: “As you know everything I do is improvising”. Liz agrees: “Yes, you adapt don’t you”. Geraldine: “I adapt as I go along, so to tell you where I’d put everything, I can’t”. As Geraldine works to fill the kettle from a jug water spills onto the surface and Hilary intervenes: “Stop a moment Geraldine”. She wants Geraldine to consider doing things differently, making a case for her to place the frame to the side, supporting herself on the kitchen surface and to “try it that way”. Geraldine responds quietly, looking down: “Yes, if you say so, I’ll try it”.

So subject-Geraldine is actively working to sustain the associations that produce ‘competent Geraldine’, a network that seems in danger of falling apart as the session progresses. The network effects producing ‘competent Betty’ and those heterogeneous associations and material effects producing ‘incompetent Geraldine’
are in tension (Mol 2010). We cannot say that the network which produced ‘competent Geraldine’ is completely severed (Strathern 1996); there remains a partial connection. But Hilary and Liz, it appears, are doing work to “reterritorialize” ‘competent Geraldine’ as a compliant patient within a professional framework that matches their system of thought and work (“sometimes we recommend”) (Fox 2002: 353), perhaps so she can be safe when she goes home. Geraldine, and Hilary and Liz are learning about Geraldine as a body that does (Mol and Law 2004: 4). For Geraldine this appears to be raw and painful. Her newly-embodied knowledge, and uncertain but developing expertise are pieced together as she immerses herself or is immersed in new practices of doing the body. Is Geraldine motivated? ‘Motivated’ patients are expected to be (pro)active, yet compliant with rehabilitation regimes, and must appreciate when and how to take or relinquish control (see Maclean et al. 2002 for comments on the views of rehabilitation professionals). Here, we see subject-Geraldine migrating between ‘active’ and ‘compliant’, ‘competent’ and ‘incompetent’ in ways that exemplify how the embodied self may actively fashion both itself and the world around it, and conversely be shaped by the “biophysical and social world” in the collaborations and collectives of neuro-rehabilitation (see Fox’s reflections on Deleuze and Guattari and body-self 2002: 349).

In the final section, we go on to examine in more detail how the body-self may be established, then ‘redrawn’ through dynamic testing by an active, experimenting patient (Fox, 2002).

A body divided and a body re-composed

Jim is 65 years old. He had a stroke four weeks ago which has affected his mobility and communication – he has aphasia, impairing his ability to write, and to select and say the right words. Here we examine extracts from two sessions, one with a speech
and language therapist (SLT, Mary), and the other with an occupational therapist (OT, Judy). As Winance (2006: 56) shows us a disabled person may be opened up, divided, explored and shaped, their integrity suspended, so as to be re-defined in terms of relations between heterogeneous entities. We will see too how a division of professional labour (Johnson 1972) is integral to dividing up and re-composing in rehabilitation practice. The body Jim “has”, in the form of language-in-the-brain is the focus of speech therapy activities; while the body Jim “is”, is brought to light in the OT session with Judy. Or as Callon and Rabeharisoa (1999: 160) have it, Jim is: “a body which does not cease to be a person”

Having a body: language-in-the-brain

Jim, his wife Philippa and Mary the SLT are seated around a table in one of the therapy rooms. Some papers, a spiral-bound workbook and a box of coloured photographic cards are out on the table. Mary reminds Jim that they are going to work on “the writing side of aphasia”, explaining that they will continue with work from a previous session. Here, Mary will say the first sound of a word, while Jim has to choose the picture denoting the word which starts with that sound from a selection of nine each with its name set out beneath the image. Jim and Mary work through a number of these sound-picture-word choice tasks. Sometimes Jim repeats the sound quietly to himself, while mulling over the pictures, doing the internal, invisible work needed to make the right connections. Mostly he chooses correctly, occasionally he makes a mistake, perhaps also saying a wrong word. For example, in response to Mary’s “m” he says “cow” and “ball”, so Mary restructures the task or re-presents the sound so as to help him self-correct.

---

1 “un corps qui ne cesse d’être une personne”
Next Mary flips through the workbook turning to a page of pictures without the names underneath, and they continue as Mary makes some notes. They finish this work and Mary sums up: “These are really good, you’re getting much quicker as well”. Work on the correspondences between sounds and their visible or visualised orthographies forms the first part of this session. Now they move on to another aspect of language-in-the-brain: finding and saying the right word to express meaning. So Mary asks Jim to think of and say words associated with categories of things. She starts by asking for “electrical items”. Jim quite readily produces a series of these words, with Mary recording them on her notepad: “Computer; TV set; kettle; microwave”. Occasionally they have a discussion about whether a word is a legitimate member of the category. When Jim seems to have run out of words, Mary asks him to “think of your kitchen at home, what electrical items are in there?” This seems help, as Jim produces several more items, but then there are long pauses as he searches for more words. Mary sums up again: “Well done, that was much better than you’d done previously”. And then she wants him to move on: “You might find this slightly harder; the category is emotions or feelings”. Jim has great difficulty saying any words in this category, and long silences and sighs ensue. Mary makes suggestions, gives cues and hints but Jim is stuck. “Emotions are hard, these words we can’t imagine as well” says Mary. Jim talks about being able to visualise things in the kitchen, and being able to imagine using these items.

So words not only have a certain materiality in the muscles of speech and articulation of sounds (Law and Moser 2011), they exist too in a world of neural networks and semantic associations made visible and audible through orthographies and speech.
Much as Betty’s body work involved testing and tinkering, and so too does Jim’s, albeit in this inner world of work on language-in-the-brain. Mary extemporises and prompts with words and word fragments, enabling Jim to respond, making associations, re-forming networks and producing transformation (“that was much better than you’d done previously”). As in Horton’s (2008) study of aphasia therapy, Jim is active in strategically laying claim to the time needed for processing meanings, making connections and working to produce these words. Both Jim and Mary make continuous efforts and adjustments, drawing on visible, audible and imagined material resources to produce the effects we see. But how does their work hang together? What of control, co-ordination and the exercise of professional power? As Mol (2010: 264) points out “co-ordination is a strategic term that hints at the existence of a centred strategist, someone with an overview. A network, however, does not have a single centre”. Latour (2005: 64) proposes that power must be produced, not seen as a thing or explanation in itself: “asymmetries exist, yes, but where do they come from and what are they made out of?” Here we see how the material paraphernalia of language therapy (workbooks; picture cards; words), language theories (semantics) and therapy schema (cognitive rehabilitation) come together with the human actors present to produce the relational effects of ‘power over’ working on language-in-the-brain (see Gardner and Cribb 2016 for a discussion of ANT-inspired understandings of power).

So, in this SLT session, Jim’s communication is deconstructed. Words are isolated, performing not as communicative entities but rather as the body work of language-in-the-brain. So how do words figure in the re-composition of the body Jim is? And how does Jim become an active, experimenting agent in the work of re-composition?
Some days later we follow Jim to a session with Judy, an OT. Jim and Judy are in the kitchen on the in-patient rehabilitation unit. The kitchen is set up with an adjustable table, surfaces and spaces to allow wheelchair access, but otherwise it is like an everyday kitchen with cooker, fridge, cupboards and shelves full of cookbooks. Judy and Jim negotiate the seating arrangements as Jim manoeuvres himself in the wheelchair to sit at the table. Judy: “I’ve got several cookbooks here, so we’re going to plan a meal for next week. Can you see them up there?” Jim scans the titles on the shelf: “I know what I want” Jim says, followed by a deep sigh. Judy suggests getting down a few cookbooks so Jim can choose. He picks up ‘The Complete Cookbook’, saying: “That’s more like it”, takes the book, places it on his lap, opens it up and starts flicking through the pages. “Haven’t they got salmon?” he wonders aloud. Judy suggests using the index at the back. Jim runs his finger down the index lists, turns a page and carefully scans the contents. He finds what he wants. “I want that”, he says, pointing, “I want that plus sauce, and potatoes with it.” They agree that Jim will make lunch for him and Philippa. “I’ll make this for her, and just some beans and peas”. Then he and Judy work out what else is needed. Jim is having some trouble with finding the word for one of the vegetables. “I’ll have asparagus, not beans – what are they called?” Judy and Jim work together to try and identify and name the vegetable he has in mind – writing cannot help; Judy asks “what colour is it?”; and then Jim suggests looking for a tin in the cupboard. All to no avail, as Jim gets more and more frustrated: “What the hell are they called…cor blimey!” Judy suggests Jim tries drawing the word he has in mind. He starts to draw, saying “stalk on there” as he goes. “Sweetcorn!” exclaims Judy. After this they work together to write a shopping
list for the meal. “Do we agree with that?” asks Jim, “take me about three hours to do that”.

So we see a transformation. The body Jim “has”, the focus of SLT work on language-in-the-brain, becomes the body Jim “is”, as he deploys language to test the links making the body, and the links that make the world of Jim the person (Winance 2006: 63). In the OT session, connections with a set of heterogeneous entities – non-humans (cookbook; recipes) and humans (Judy) – afford Jim the capability to test, experiment and negotiate a performance of ‘Jim the cook’. In the work that Jim does, we can see how the properties of non-human actors are transformative in specific ways. Words in isolation – selected by Mary for their particular characteristics – afford the associations relevant for the work Jim does to improve language-in-the-brain. The cookbook affords Jim diverse connections and agency to plan and do language-in-interaction, producing re-composition.

While Jim’s stroke was a radical disruption it was also the starting point of “a series of contingent shifts and dynamic recompositions” (Moser 2009: 96), where neuro-rehabilitation may be understood as a set of ‘patient collectives’ (Callon and Rabeharisoa 1999; Moreira 2004; Winance 2006), which consist of bodies, objects and technologies drawn together in and through the activities a patient does. Loss and recovery of self can be observed in the accomplishment of these ongoing heterogeneous arrangements (Moreira 2004: 35) as agency is afforded (or not), distributed and redistributed through associations between the diverse entities in the collective (Moser 2009).
Conclusion

We have used an ANT-sensitised approach to examine patients’ active involvement in neuro-rehabilitation, exploring socio-material practices in the enactment of control over the body, choice, power and transformation. Our objective in taking the empirical approach we have, is to contribute to the understanding of active participation without attributing its ‘character’ “either to the body and its diseases or to social circumstances” (Mol and Elsman 1996: 611). Taking an ANT-sensitised approach has enabled us to re-imagine neuro-rehabilitation by exposing and exploring the various technological and material, as well as the human elements to more comprehensively re-vision them as all “… inter-related. Yet irreducible to the other” (Mol and Elsman 1996: 628). These come together in diverse associations forming networks on specific occasions to produce ‘active participation’.

This re-imagining of neuro-rehabilitation is important for understanding how ‘active participation’ may need to be understood from a sociological perspective, as a process of actively combining the values and cultural considerations of individuals, institutions and wider society with theoretically-driven, body-centred approaches to assessing impairments, and enacting situated rehabilitation work designed to promote specific transformations in the form of recovery or adaptation. We argue that existing methodological approaches to understanding ‘active participation’ have generally produced a disarticulated order in unduly limiting appropriate understandings and insights. ANT in contrast, builds a more critical and conditioned understanding of neuro-rehabilitation, “foregrounding practicalities, materialities, events” [original emphasis] (Mol 2002), and more clearly identifies who is performing what, at what time. ANT-sensitised insights help to show how an impaired body may learn to learn and re-learn through involvement in any number of enabling material practices (Moser 2009: 88), such that ‘active participation’ is produced by complex,
often precarious networks, so taking a particular character at any one time, which
suggests that efforts to standardise approaches to assessment and intervention or
count and account for optimum defined therapy ‘dosages’ (Intercollegiate Working
Party 2016; Lhose et al. 2014) in conventional ways may be misdirected.

The distribution of work between human and non-human actors, the tinkering
and transformations seen here to produce distinctive performances of ‘active
participation’ challenge any assumptions that ‘active participation’ should or can be
located in the individual. By extension, we would also caution against conceptualising
‘self-efficacy’ or ‘motivation’, as located in the individual and so open to individually-
situated remediation (Intercollegiate Working Party 2016; Dixon et al. 2007; Brands
et al. 2012). This latter position fails to acknowledge or accommodate the
heterogeneous networks inherent in producing ‘active participation’, which include
therapists’ performances as professionals (e.g. corrector, enabler, bringer of bad
news). Locating ‘active participation’ in neurorehabilitation networks instead
identifies it as more difficult, moral work, in which variables must continuously be
attuned to each other (Mol 2008).
References


Parry, R. (2004a) Communication during goal-setting in physiotherapy treatment sessions. *Clinical Rehabilitation*, 18, 668-682


<table>
<thead>
<tr>
<th>Settings</th>
<th>Patient (age)</th>
<th>Therapy type (staff present)</th>
<th>Brief summary of activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient stroke rehabilitation / Medicine for the Elderly</td>
<td>Jill (84)</td>
<td>OT (OT + OT assistant) [13]</td>
<td>Sitting / standing balance</td>
</tr>
<tr>
<td></td>
<td>Frank (67)</td>
<td>OT (OT) [12]</td>
<td>Standing balance</td>
</tr>
<tr>
<td></td>
<td>Geraldine (68)</td>
<td>OT + PT (OT - Liz; PT - Hilary) [33]</td>
<td>Kitchen assessment</td>
</tr>
<tr>
<td>In-patient specialist neuro-rehabilitation</td>
<td>Betty (34)</td>
<td>PT (PT - Anne; therapy assistant - Liv; student PT - Kate) [50]</td>
<td>Balance, trunk control and strengthening exercises</td>
</tr>
<tr>
<td></td>
<td>Margaret (49)</td>
<td>PT (PT) [30]</td>
<td>Strength / mobility training; stairs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OT (OT) [39]</td>
<td>Kitchen assessment</td>
</tr>
<tr>
<td></td>
<td>Clive (55)</td>
<td>PT (PT) [38]</td>
<td>Sit-to-stand practice; arm strength / mobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OT (OT; therapy assistant)</td>
<td>Gardening (outdoors)</td>
</tr>
<tr>
<td></td>
<td>SLT (SLT)</td>
<td>[23]</td>
<td>Dysphagia review; articulation work</td>
</tr>
<tr>
<td></td>
<td>Jim (65)</td>
<td>PT (PT) [63]</td>
<td>Gait work; walking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OT (OT – Judy) [38]</td>
<td>Kitchen / recipe / meal planning</td>
</tr>
<tr>
<td></td>
<td>SLT (SLT – Mary)</td>
<td>[37]</td>
<td>Sound-to-picture; word meanings</td>
</tr>
<tr>
<td>Name</td>
<td>Speciality</td>
<td>Age</td>
<td>Activities</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------</td>
<td>-----</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Adam (26)</td>
<td>PT (PT)</td>
<td>26</td>
<td>Reassessment, strength, balance</td>
</tr>
<tr>
<td>Jackie (67)</td>
<td>OPT (OT; PT)</td>
<td>67</td>
<td>Head &amp; neck position (PC)</td>
</tr>
<tr>
<td>Out-patient</td>
<td>George (57)</td>
<td>57</td>
<td>Gait work</td>
</tr>
<tr>
<td>specialist neuro-rehabilitation</td>
<td></td>
<td></td>
<td>Gait work</td>
</tr>
<tr>
<td>Betty</td>
<td>PT (PT, therapy assistant)</td>
<td></td>
<td>Walking + stick</td>
</tr>
<tr>
<td>Leyla (38)</td>
<td>OT (OT)</td>
<td>38</td>
<td>Driving assessment</td>
</tr>
<tr>
<td>Hetty (68)</td>
<td>SLT (SLT)</td>
<td>68</td>
<td>Speech work; functional communication</td>
</tr>
<tr>
<td>Peter (72)</td>
<td>PT (PT)</td>
<td>72</td>
<td>Back pain assessment</td>
</tr>
<tr>
<td>Hospital out-patients</td>
<td></td>
<td></td>
<td>‘Living with aphasia’ group</td>
</tr>
<tr>
<td>5 patients (4 male; 1 female)</td>
<td>SLT group therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential home</td>
<td>Eva (74)</td>
<td>74</td>
<td>Review; compensatory speech work</td>
</tr>
</tbody>
</table>

OT = occupational therapy; PT = physiotherapy; SLT = speech & language therapy