



# Green Rehabilitation Market Research Report



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## Executive Summary

“Green Care” or “green rehabilitation”, in the UK also frequently referred to as “care farming” or “social farming”, may offer an innovative and cost effective model for social and health care provision at a time of increasing cuts to traditional health and social care services. The aim of this Northumberland Uplands LEADER supported market research study was to explore whether and how a land/farm-based environment may meet the care and rehabilitation needs of people affected by a wide range of physical and mental health problems living in Northumberland, in order to provide a basis for realistic business planning in this sector.

People with a wide range of long-term health conditions took part in focus groups or individual interviews to discuss the potential of “green care” and how green care may meet their rehabilitation and social care needs. Many participants were positive that a green care setting can meet many of their rehabilitation needs and that this environment is likely to help them and others focus on their abilities, rather than their impairments. Lack of individualised care, cost and difficulty accessing services by public transport were identified as the biggest barriers to attending a green care service. There was strong consensus amongst potential client groups that while a land-based environment seemed to offer attractive opportunities, a land-based environment is secondary to their need for a person-centred, health care professional-led specialist rehabilitation service. Importantly, people with different health condition had very different views of green rehabilitation and preferences for services and how they would like to attend them. This clearly emphasises the message that one size definitely doesn’t fit all. Study participants also expressed explicitly that they did not want to work in a farm environment/be involved in farming in any way, but that they would feel confident in a smallholding-type environment the development of which they had an opportunity to influence.

# Report

## Study Background

Green care/green rehabilitation has been described as an innovative approach to enterprise creation and development, which has the potential to make farming +/- forestry more sustainable and provide opportunities for employment and the development of skills. Importantly, due to its position straddling both farming/forestry and social care, social farming facilitates the development of skills by employees and service users in multiple areas. This can help improve both service users' and staff employability.

In addition to its income-generating capacity for organisations and individuals, social farming environments can provide the basis for bringing together people from different health and social backgrounds, as well as different age groups, to help individuals and communities become more resilient and sustainable. There are examples of "social farms" becoming a community resource, and an environment that stimulates creativity and entrepreneurial spirit in young people.

Green rehabilitation is based on the observation and growing evidence base that exposure to natural green environments is therapeutic [1-4] and that humans benefit from interacting with animals [3,5,6]. Green environments and contact with animals are now used deliberately to facilitate positive changes in people from a wide range of health and social backgrounds, most commonly for people with mental health problems and those at risk of social exclusion [7,8]. Green care can take many forms and broadly includes the use of gardening (amenity, vegetable and/or ornamental), interaction with animals, and with green spaces in a wider sense [7,8]. Depending on individual service users' needs and goals, this interaction could be very active, such as in digging over a vegetable plot, exercising in a natural environment, or looking after horses, or it could just involve being in a green outside space, perhaps bird watching, being present in a garden, listening to water, or watching animals graze.

In the UK and internationally, most green care/social farming initiatives are provided for people with mental health problems and people at risk of social exclusion (mostly young people who are not in employment, education, or training), and the great majority of the current research evidence is in this area. However, in the UK many green care organisations now also offer services for people with learning difficulties and other special educational needs [9], and a few support people with physical disabilities. The scale of operations is diverse, with some organisations catering for three clients three days per week, to those opening their doors to hundreds of people every week. The service provided by different organisations in this field also differs greatly, from provision of rehabilitation programmes to help ex-service personnel recover from mental and physical trauma on six acres of land, to partnerships between big commercial farms, further education colleges and food retailers to add value to what each are doing and to make it more sustainable [10].

Northumberland is an extremely rural county with a population density of 63 people per km<sup>2</sup>, lower than any other local authority in the North East, and the seventh lowest population density of all local authorities in England [11]. Importantly, some 95% of Northumberland's population live in only around 5% of its area, resulting in wide stretches of very sparsely populated countryside, indeed, and making health and social care services difficult to access for many people living in the remoter parts of the county [12]. Northumberland's population also has a greater percentage of people over 65 than the English average, with the discrepancy predicted to rise further [11], resulting in a higher demand for services for people with long-term health problems here than in other parts of England.

In an effort to maximise the use and productivity of Northumberland's most abundant asset, i.e. farmland and open countryside, while at the same time improving access to health and social care services for people living in rural areas, Northumberland County Council has made efforts to explore and promote the possibility of using farm-based green care to benefit people with long-term health conditions.

At the same time, organisations either already providing some social farming services, or aspiring to do so, are not currently in a position to engage in realistic business planning and the development of strategies, because of a lack of market research that applies to potential service users in the local area. Not surprisingly, our contacts with other individuals and organisations wanting to develop social farming in the county confirm that this is a situation we all share. While some information and figures are available for other parts of the UK and other countries, this information is not likely to be transferable to this region for the reasons outlined above.

Against this background, this market research project, funded by Northumberland Uplands LEADER, was undertaken with a view to informing service development by different existing and/or aspiring green care service providers in Northumberland. The

aim of this project was to undertake market research with potential green care/social farming service users and commissioners to explore the type of services people with long-term health conditions in Northumberland are looking for, whether green care can meet the needs of this client group, and where and how they would like to access these services. Ultimately, the findings are intended to serve as a basis for realistic business planning across this sector in Northumberland.

A potential service user group we were particularly keen to engage with in this context were people affected by acquired brain injury. Most traumatic brain injuries are sustained by young men aged 18-25, in the pursuit of leisure activities, as a result of road traffic accidents, and increasingly, as a result of injuries sustained in the armed forces. We felt that this group was of particular relevance, as there is evidence that their needs for rehabilitation, stimulation and meaningful occupation are not met in traditional/currently available rehabilitation settings. This is particularly pertinent at a time when the UK government is pushing for people with disabilities to (re-) join the workforce while at the same time making stringent cuts to disability-related benefits.

## Research evidence

A range of rigorous research approaches, including randomised controlled trials (RCTs), now support the claim of the health benefits of green rehabilitation for people from a variety of health and social backgrounds. Some of these studies are not specific to people with health problems [1,2], others are. A rigorous and highly regarded cross sectional ecological study [2] of all of England showed that greener living areas were generally associated with better health as measured by the standardised morbidity rate ( $p < 0.000$ ). An RCT [3] into the effects of animal assisted therapy for people with depression provided evidence of significantly increased self-efficacy ( $p = 0.05$ ), coping ability ( $p = 0.03$ ) and mood ( $p = 0.02$ ) in the treatment group over the control group, with greatest improvements seen in those who sought the most physical contact with the animals ( $p = 0.03$ ).

Studies of the influence of interaction with dogs on human heart rate, blood pressure and stress hormones provide support for the calming and stress-reducing effects of animal assisted therapy [13-17]. Recent meta-analyses provide further evidence of the health benefits of green care: a recent meta-analysis of ten studies involving 1252 service users in the UK demonstrated highly significant improvements in self-esteem and mood (both  $p < 0.00001$ ) [4]; another rigorous review [5] also found a statistically significant decrease in symptoms related to depression in those engaged in green care.

## Methods

### Researchers

To give the reader the opportunity to assess the relevance, and value of this piece of market research, we will outline who was involved in the project.

The project was conceived, developed and managed by Dr Dorothee Debuse (DD), PhD, Chartered Physiotherapist and Chair of Horse Power for Ability, a Northumberland-based third sector organisation providing specialist physiotherapy services for people with movement disorders. In addition to her professional insight into the rehabilitation needs of people with long-term health conditions, she brought to this project a strong track record in research in her capacity as a senior lecturer in physiotherapy at Northumbria University where she supervises PhD students, is a member of the Faculty of Health and Life Sciences Research Ethics Panel, and the research lead for the pre-registration MSc Occupational Therapy and MSc Physiotherapy programmes.

The majority of data collection and data analysis was undertaken by Kelly Heartshorne (KH), MSc, an Occupational Therapist with a special interest in green care, service development by service users and previous experience of both project management and social farming research.

### Ethical considerations

Throughout, the ethics aspects of this study were informed by DD's expertise as a research ethics reviewer and research ethics panel member in the Faculty of Health and Life Sciences at Northumbria University.

As this study was a service development project (and not research) by a third sector organisation, which recruited participants from other third sector organisations rather than the National Health Service, ethical approval by an "official body", such as a university or the National Research Ethics Service, was not necessary, and therefore not sought [18]. However, there was no getting away from the fact that we were seeking the views of people, many of whom, by the nature of their health conditions, would be defined as "vulnerable adults". This meant that we needed to adhere to strict ethical



principles in order to protect the interests, rights and dignity of the people we were seeking information from. In order to achieve this, we invited leaders of the third sector organisations through which we sought to recruit study participants to act as gate-keepers in the recruitment process by reviewing the project proposal and participant information. Some suggested minor changes to the information provided to potential participants as part of the recruitment process (before data was collected), which were implemented.

In line with health research guidelines, potential participants were given written +/- verbal information about the study and then had the opportunity to go away and discuss with others whether they wanted to take part in the study. On the day of data collection they had another opportunity to ask questions before they were asked to give written informed consent to taking part in the study.

## Recruitment of participants

To access as many people as possible, we worked with local third sector organisations for and/or of people with long-term health conditions in Northumberland who helped us identify existing groups of people and individuals who might be interested in participating in the study. We invited people with long-term health conditions who were able to express themselves verbally either on their own, or with the support of a carer, and were comfortable doing so either in a group situation or a one-to-one interview. Carers who attended with people with long-term health conditions were also invited to share their views, not only to add insight into the perspectives of people with long-term health conditions, but importantly, because carers of people with long-term health conditions have been shown to be in need of specialist services, themselves [19,20] and are, therefore, potential service users.

In line with the Mental Capacity Act 2005, mental capacity to consent to taking part in the study was assumed unless there was evidence/advice to the contrary; all study participants had mental capacity.

Unfortunately, due to a seven-week delay in the approval of the project by DEFRA, recruitment of participants could not start until after Christmas 2011.

## Data collection and analysis

Data was collected from people with a variety of long-term health conditions by Kelly Heartshorne (KH), the contracted researcher, in Spring and early Summer 2012. To facilitate participation by potential service users, where possible, data collection was arranged at the third sector organisation where participants met regularly and were already familiar with the environment and each other. Where this was not possible other

easily accessible venues were used, such as a social club and a fully accessible health club.

Participants were given a choice between attending a focus group or an individual interview, and all data from people with long-term health conditions was collected in six focus groups and seven individual interviews (some of them telephone interviews) across different locations in Northumberland. In order to safeguard the anonymity of study participants we cannot provide information on data collection sites.

The interviews and focus groups were semi-structured and based on the same key areas of enquiry which are outlined in the box below. The exact wording and order of questions differed between groups, however, in order to accommodate individual group dynamics.

**Key areas of enquiry:**

- What kind of services potential social farming are service users and commissioners looking for?
- How much are they willing to pay for these services?
- How regularly/often would potential service users like to use these services?
- How far are they willing to travel to access these services?
- How will they access the services (car, taxi or public transport)?
- What support would the carers of people with long-term health problems like, and how this can be provided in a social farming environment?

At all data collection meetings with potential service users, participants were offered refreshments and an effort was made to create a friendly atmosphere that would encourage disclosure and open discussions. Unlike in other focus group investigations [21-23], there was no overt or covert pressure by some members of groups affecting other participants' responses in this study. On the contrary, participants frequently agreed with and built on what other members of the group had said, and many expanded on experiences and aspirations. This can be taken as genuine consensus, as opposed to less assertive or vocal members conforming to majority opinion or to particularly dominant participants' views [24], making the findings truly representative of potential service users' opinions.

The focus groups and interview were audio-recorded and transcribed by KH. Both KH and DD were involved in data analysis.

## Findings

From participants' contributions it was clear that, across health backgrounds, people affected by long-term health conditions share frustrations with the services currently available to them, and with the difficulty both of accessing those services, and of becoming aware of them, in the first place. While this is an important finding in itself, which we will write up for publication in an international peer-reviewed rehabilitation journal, the focus of this report is on green rehabilitation. Therefore, people's frustration with existing conventional health and social care services, as well as their experience of their own disability/health condition will not be expanded on in this report.

It is important to note that in spite of considerable differences in the socioeconomic background prevalent in the different locations where data were collected, participants expressed themselves on the same themes across groups and locations. However, while difference in location and socioeconomic background did not seem to make a big difference in the perspectives and preferences expressed, it was apparent early on that difference in health background did. For this reason, findings will be broken down according to potential client groups. Where people with different health conditions shared characteristics and views, these are combined.

To provide a quick overview of potential service users' preferences in relation to the key areas of questioning outlined earlier, a summary of findings will be presented in table format, followed by a more detailed description of different potential client groups' views and preferences. A brief outline of health conditions is given at the beginning of each section, to help those readers who do not have a background in health or social care interpret the findings in context, and quotes are used to illustrate the authenticity of what is reported.

Feedback from commissioners of health and social care services will be reported separately.

## Tabulated overview of findings according to client group

Question:		What kind of services (ethos and organisation)?
People with	<b>Acquired brain injury including stroke</b>	<ul style="list-style-type: none"> <li>• holistic and person-centred: physical, emotional, social and vocational rehabilitation/reablement</li> <li>• tailored to the ability and pace of the individual</li> <li>• needs to be fully accessible, without highlighting disability</li> <li>• opportunity to support others and be supported</li> <li>• service to provide a sense of purpose; a land/farm based service could facilitate this</li> <li>• opportunity to interact with animals</li> <li>• opportunity to progress with personal goals and experience achievement</li> <li>• opportunity to rest/take time out</li> </ul>
	<b>Multiple sclerosis</b>	<ul style="list-style-type: none"> <li>• holistic and client-centred</li> <li>• opportunities to explore their abilities, and demonstrate these at a service</li> <li>• Do not wish to attend a service alongside others with MS exclusively</li> <li>• needs to be fully accessible, without highlighting disability</li> <li>• opportunities to have contact with animals</li> <li>• choice of interesting activities</li> <li>• opportunity to rest/take time out</li> </ul>
	<b>Parkinson's disease</b>	<ul style="list-style-type: none"> <li>• holistic and client-centred</li> <li>• opportunities to experience aim and purpose</li> <li>• for a range of physical conditions</li> <li>• a social enterprise model, green rehabilitation service</li> <li>• opportunity to interact with animals</li> <li>• opportunity to learn skills to a high standard</li> <li>• opportunity to rest/take time out</li> </ul>
	<b>Mental health problems</b>	<ul style="list-style-type: none"> <li>• opportunities to socialise with a range of others in small groups</li> <li>• need welcoming, understanding and supportive staff to create a relaxed atmosphere</li> <li>• client-centred service where their voice is respected</li> <li>• service to facilitate opportunities for progression and achievement, whilst allowing relaxation</li> <li>• service to provide a sense of purpose; a land/farm based service could facilitate this</li> <li>• opportunity to engage in personally interesting activities: mix of animal care, horticulture and art/craft</li> <li>• opportunity to work to at own pace</li> <li>• opportunity to rest/take time out.</li> </ul>
	<b>Learning disability</b>	<ul style="list-style-type: none"> <li>• opportunity for occupation in practical activities</li> <li>• opportunity to explore new interests and develop skills and knowledge</li> <li>• opportunity to socialise through teamwork</li> <li>• opportunity to be involved in practical animal care.</li> </ul>

## Tabulated overview of findings according to client group cont.

Question:		Services for carers?
People with	<b>Acquired brain injury incl stroke</b>	<ul style="list-style-type: none"> <li>• Would like service to offer opportunities for carers to engage, if they are supporting individual to attend.</li> <li>• Many would attend without a carer.</li> <li>• Would like a service to offer occasional opportunities for families to participate in activities, so that their families can witness their ability/ achievements.</li> </ul>
	<b>Multiple sclerosis</b>	<ul style="list-style-type: none"> <li>• Would like service to offer opportunities for carers to engage, if they are supporting individual to attend.</li> <li>• Some individuals would prefer the opportunity to attend independently of their carer.</li> <li>• Would like a service to offer occasional opportunities for whole families to participate in activities.</li> </ul>
	<b>Parkinson's disease</b>	<ul style="list-style-type: none"> <li>• Would prefer to attend independently of carer, as feel this would provide respite for carer.</li> <li>• If attending with carer, would like carers to have opportunity to engage in high quality activities</li> </ul>
	<b>Mental health problems</b>	<ul style="list-style-type: none"> <li>• None required, those interviewed live independently.</li> <li>• Would like service to open doors to family on occasions, so they could witness service users succeeding in activities.</li> </ul>
	<b>Learning disability</b>	Receive care from support workers. No service required by those interviewed.
Question:		Residential facilities?
People with	<b>Acquired brain injury incl stroke</b>	Younger people with ABI are very keen on residential facilities
	<b>Multiple sclerosis</b>	None required
	<b>Parkinson's disease</b>	None required.
	<b>Mental health problems</b>	None required
	<b>Learning disability</b>	None required.

## Tabulated overview of findings according to client group cont.

Question:		Acceptable cost?
People with	<b>Acquired brain injury incl stroke</b>	<ul style="list-style-type: none"> <li>Many are not currently aware of direct payments/personal budgets</li> <li>Would be keen to allocate personal budget for a land-based service if it was felt to be of benefit</li> </ul>
	<b>Multiple sclerosis</b>	<ul style="list-style-type: none"> <li>Would consider allocating health/care budget to a service based on land/farm environment.</li> <li>Would consider paying £20 - £30 per session, if they felt a service offered benefit.</li> <li>Would expect a high quality and good value service.</li> </ul>
	<b>Parkinson's disease</b>	<ul style="list-style-type: none"> <li>Would not pay for standard attendance</li> <li>Would pay to attend 'professional' courses where able to learn new crafts to a high standard</li> <li>Consumer driven: would expect high quality teaching and facilities</li> </ul>
	<b>Mental health problems</b>	<ul style="list-style-type: none"> <li>Would not pay to attend a service, would not be able to afford to do so.</li> <li>No knowledge of direct payments or personal budgets. If they were entitled to some, they would consider allocating spending some of it on social farming/green care service.</li> </ul>
	<b>Learning disability</b>	<ul style="list-style-type: none"> <li>Would not want to pay to attend a service: would not be able to afford to do so</li> <li>No knowledge of direct payments/personal budgets, but if had control of personal budgets would allocate funds to attend a farm/land based service</li> </ul>
Question:		Access – travel time?
People with	<b>Acquired brain injury incl stroke</b>	<ul style="list-style-type: none"> <li>Younger people would travel for up to an hour, maybe longer, from door to door. Some younger potential service users are so keen they'd like the opportunity to stay over night to minimise need for travel.</li> <li>Older people with stroke would prefer to travel no more than half an hour</li> </ul>
	<b>Multiple sclerosis</b>	Would travel a maximum of 20 miles to a service, though would prefer a shorter distance.
	<b>Parkinson's disease</b>	Would travel a maximum of one hour, but would prefer less.
	<b>Mental health problems</b>	Would prefer service to be local, preference for 5 minutes away, If interest was great enough, would consider travelling 20 – 30 minutes door to door.
	<b>Learning disability</b>	Would travel up to a maximum of 1 ½ hours each way to attend a land/farm based service

## Tabulated overview of findings according to client group cont.

Question:		Access – how often, when?
People with	<b>Acquired brain injury incl stroke</b>	<ul style="list-style-type: none"> <li>• younger people with acquired brain injury would like to attend several times per week, for half or full days</li> <li>• older people with stroke would like to access weakly, or perhaps twice a month</li> </ul>
	<b>Multiple sclerosis</b>	<ul style="list-style-type: none"> <li>• Would like to access twice a month for half a day at a time.</li> <li>• Would like service to be flexible, allowing individuals to attend on an ad hoc basis, rather than on fixed days.</li> <li>• Attendance would be driven by interest in the activities offered. Would like a schedule of activities in advance.</li> </ul>
	<b>Parkinson's disease</b>	<ul style="list-style-type: none"> <li>• Would like opportunity for flexible attendance.</li> <li>• Attendance would be driven by interest, would like to know what's on before they go.</li> </ul>
	<b>Mental health problems</b>	<ul style="list-style-type: none"> <li>• Would like to attend ½ days, preference for afternoons.</li> <li>• Would like to attend regularly, between 1 and 5 times weekly.</li> <li>• Would require flexibility and no pressure about when to attend.</li> </ul>
	<b>Learning disability</b>	<ul style="list-style-type: none"> <li>• Would like to attend on a regular basis, between 2 – 5 times every week.</li> <li>• Would like to attend on fixed days, driven by consistency and routine.</li> <li>• Would like to attend on a long-term basis.</li> </ul>

## Tabulated overview of findings according to client group cont.

Question:		Access – means of transport?
People with	<b>Acquired brain injury incl stroke</b>	<ul style="list-style-type: none"> <li>Older people with stroke may attend by car but would prefer a minibus to pick them up from a convenient location near home</li> <li>Younger people with acquired brain injury would attend by public transport, so would require service to be on a good bus route, or for service to provide transport from pick up point.</li> <li>Having to pay for other transport would make expenses prohibitive</li> </ul>
	<b>Multiple sclerosis</b>	<ul style="list-style-type: none"> <li>Would access a service by car, mainly with the support of their carer or partner.</li> <li>Some individuals would like a service to offer transport on occasions, to provide individuals with opportunity to access independently of their partner</li> </ul>
	<b>Parkinson's disease</b>	<ul style="list-style-type: none"> <li>Would prefer to access independently using public transport or service bus.</li> <li>Would need regular route and service near bus stop. Otherwise would access service via carer driving</li> </ul>
	<b>Mental health problems</b>	<ul style="list-style-type: none"> <li>Would prefer to access a service on foot, would like service to be situated within short walking distance.</li> <li>Otherwise would travel on public bus to attend. In that case the route would have to be regular, and the service be situated next to a bus stop. Having to pay on public transport may prevent attendance.</li> </ul>
	<b>Learning disability</b>	<ul style="list-style-type: none"> <li>Would attend by public transport, so would require service to be on a good bus route, or for service to provide transport from pick up point.</li> <li>Would like to access by bus, due to free bus pass. Needing to use other forms of transport with associated cost would prevent attendance.</li> </ul>



## Summary of suggestions of environment, activities, animals and facilities across health backgrounds

Potential service users had definite likes and dislikes and expressed themselves very explicitly and without prompting or suggestions by the interviewer on what kind of environment, activities, facilities and animals they are after. The table below provides a summary of their preferences.

	Service users	
	would like	would definitely not like
<b>Farm</b>	<ul style="list-style-type: none"> <li>• Small-holding, ideally organic</li> <li>• small visitor attraction that would offer the opportunity for integration with people with other health problems, and without health problems</li> </ul>	<ul style="list-style-type: none"> <li>• Big/working farm (except people with learning disability)</li> <li>• Farm where animals are raised for slaughter</li> </ul>
<b>Facilities</b>	<ul style="list-style-type: none"> <li>• need to be fully wheelchair accessible</li> <li>• Space to get out of the cold and wet</li> <li>• Room offering possibility to lie down and rest/sleep</li> <li>• Farm shop (to sell farm produce and engage with the public)</li> <li>• Café (to sell farm produce and engage with the public)</li> </ul>	
<b>Activities</b>	Animal husbandry <ul style="list-style-type: none"> <li>• Looking after small and medium-sized animals</li> <li>• Bee-keeping</li> </ul> Horticulture <ul style="list-style-type: none"> <li>• Ornamental</li> <li>• Fruit and vegetables</li> </ul> Arts and Crafts <ul style="list-style-type: none"> <li>• Cooking/preserve making</li> <li>• Woodwork: bird and bat boxes etc</li> <li>• Painting</li> <li>• Textile crafts</li> </ul>	<ul style="list-style-type: none"> <li>• Bingo</li> <li>• Just sitting around, drinking tea</li> </ul>
<b>Animals</b>	Small to medium-sized animals: <ul style="list-style-type: none"> <li>• Chickens, ducks</li> <li>• Dogs</li> <li>• Sheep</li> <li>• Goats</li> <li>• Small-medium horses, ponies, donkeys</li> </ul>	Big animals: <ul style="list-style-type: none"> <li>• Cows (except people with learning disability)</li> </ul>

## People affected by acquired brain injury (ABI)

Acquired brain injury is damage to the brain that is acquired after birth and may be the result of a traumatic brain injury, such as a car crash, or a non-traumatic brain injury such as a brain tumor, stroke, or encephalitis. By the nature of their condition, people with ABI share a sudden much deteriorated state of health. The majority of people sustaining a brain injury as a result of trauma are men aged between 18 and 25, with a significant and increasing number of injuries sustained during active service in the armed forces.

Depending on which areas of the brain are affected, the damage may result in problems with movement, speech, behaviour, organisation, cognition and/or emotion. Following their injury, people with ABI start a slow journey of adjustment and rehabilitation/reablement. In older people with stroke the area affected is usually smaller than in people with a traumatic brain injury. As a result, their deficits are more discreet and less complex than in people with a traumatic brain injury. Many (younger) people with traumatic brain injury spend some time in a coma due to the widespread damage to their brain. Following this, their initial rehabilitation usually involves many months in hospital, and their overall recovery takes years.

Even a mild injury can have a significant impact on a person's daily functioning for the rest of his/her life. The challenges faced by people affected by ABI are multi-factorial; that is, the problems are not just emotional or cognitive but spill over into community living and vocational problems. Loss of identity is also another common characteristic of people affected by ABI as they transition through the rehabilitation/reablement process and try to reintegrate into the community and work. The complexity of their injury and the subsequent areas of functioning affected mean that in order to reach their full potential to participate in all areas of life, people with traumatic brain injury need ongoing and specialist rehabilitation/reablement support. While many people with a traumatic brain injury make a remarkable recovery bearing in mind the severity of their initial injuries, very few ever regain their pre-injury state of health and ability.

What became apparent from their contributions was that participants with ABI shared a keen desire to return to their pre-injury state of health and ability, or as close to it as possible. As a result, they were all highly motivated to contribute to this project and keen to be involved, to the point that one person decided to contribute to two focus groups.

## Preferences of people with acquired brain injury

### ***What kind of services do individuals with acquired brain injury want?***

#### **They want services to be person-centred and holistic**

People with acquired head injury, including stroke, have a wide range of potential disabilities, depending on which area(s) of the brain were affected. Particularly against this backdrop it is not surprising that potential service users expressed that services would have to meet their individual needs. The key is not to provide a service for “people with acquired brain injury”, but for Tom and Jill and Shaun and Kev.

[complaint about a different service] *“they decide on time [they can spend on you] and not the person. I think if they decided on the person that would be totally different.”*

*“You're all individuals, you're not a group. You don't feel like a group of misfits, you're all individuals ... and I think that's really important.”*

*“I think it would be good if you had a choice [about ways of doing things].....*

*Respecting individuality.”*

This demand for a person-centred service includes individuals' needs to take rest periods at a time that suits them, and the “space” to work at their own pace.

*“Cause if you get tired...you just fall asleep, so it should be allowed to sleep.”*

*“Here they do like enforced breaks every 45mins....and that doesn't suit me. I get it suits other people, its important to understand that everyone's different and some people are going to want to work some ways, and others need a break every forty five minutes. A bit of flexibility, letting people work in whatever way works best for them.”*

#### **People with acquired brain injury want service to provide the opportunity to engage in a range of stimulating activities**

People with acquired brain injury expressed explicitly that they wanted to have the opportunity to engage in different activities that are of interest to them and that they probably wouldn't want to do the same thing every day.

*“There would have to be a wide range of opportunities available, so that you weren't just signing up to one thing...you could choose between a range of things there, that reflect your interests.”*

## **Young people with acquired brain injury want a rehabilitation service that helps them rebuild their lives**

Particularly younger participants with acquired brain injury want a service that is meaningful and relevant to them. They expressed explicitly that this would include supporting service users to work towards and achieve goals that are meaningful and specific to them as individuals. They seek the relevant stimulation to progress their cognitive, creative and physical abilities, and consider that newly and/or re-developed skills would help them overcome feelings of a 'loss of purpose' which they have experienced.

*"When you're achieving your goals it obviously boosts your confidence."*

*"It [green rehabilitation] could like help with building confidence up and your self-esteem. Doing stuff that would make you feel like you've got a purpose, which I haven't felt for a while."*

Young service users with acquired brain injury were quick to recognise the potential in a land/farm-based environment for (aspects of) vocational rehabilitation. For many this was not only an important step to help them become socially and financially independent; the associated "productivity" was linked to feelings of self-esteem, achievement and the ability to "give something back":

*"The whole concept [of green rehabilitation] is a good idea, because a lot of people with brain injury find themselves after the job role that they had prior to the accident...they can no longer carry out. And then you're left frustrated, knowing you can't do the job that you did have and then looking for a new vocation. So...something that somebody can go hands on...'cause getting work placements with a brain injury is extremely difficult. So somewhere that people can go, and at least try the horticultural side, and the looking after the animals and that...it might give them a new vocation that they didn't realise they had an interest in, and give them some worth back. Because a lot of people with injuries find that they can't carry out their previous job role."*

*"I think having a work placement there [green rehabilitation centre] would definitely give me a sense of achievement. I don't feel like I'm putting a contribution ... but when I'm working in the shop it feels like I'm giving something back. It gives me my self-respect back."*

***How much would individuals with acquired brain injury be prepared to pay to attend a service?***

The majority of potential service users with acquired brain injury did not have a personal budget at the time of data collection and said they could ill afford to pay for services at that time. However, participants of all ages felt that green rehabilitation could be very worthwhile and beneficial, and many said that if they did have a personal budget they would be keen to use it to attend a green rehabilitation service if it was meeting their needs and expectations.

*“If he’s getting benefit out of it and enjoying it, then yes I would pay. The cost of it wouldn’t come into it, wouldn’t matter if he was enjoying it”.*

*“Yes I would agree with that.”*

*“It’s about the quality of what is being provided.”*

*“Yeah [I would use my personal budget to pay for it] ‘cause it could be part of your rehab, couldn’t it.”*

*“I think I’d like to find out how beneficial it was first, before you made a decision. Sort of like testing the water, dipping your toe in first.”*

***How often would individuals with acquired brain injury wish to access a service, and when would they like to do so?***

Potential service users with ABI expressed a wide range of preferences, and there seemed to be a split between the ages. Young people with traumatic brain injury tended to want to access a green rehabilitation service three to five times per week, for full or half days, depending on their fatigue levels.

Older people with stroke seemed to have less of a drive for rehabilitation, as well as better social networks. As a result, they were not so dependent on attending a green rehabilitation service, and this was apparent from their prospective attendance. While some would like to attend on a weekly basis, the majority saw themselves attending perhaps twice a month.

This difference in preferred attendance patterns may also be reflective of the fact that older people with stroke tended to have a greater disposable income and were able to engage in leisure activities which younger people did not have access to. As a result, older people with stroke tended to view a green rehabilitation service as an addition to their lives, rather than core to developing their physical and social functioning.

***Access: How would individuals with acquired brain injury like to travel to a service?***

Again there was a split in ages: Younger people with acquired brain injury would come by public transport, and therefore depended on good bus links, or a minibus pick-up from a place that was easy to get to. Interestingly, young people with acquired brain injury felt that expensive transport, or otherwise difficulty getting there was the biggest barrier to attending.

Older people with stroke were more likely to either drive themselves, or have a spouse who was happy to drive. However, as many of them also had other health problems, such as diabetes, they were not keen to travel too far by car, and would prefer to be picked up by minibus from a convenient location near their homes.

***Access: How long would individuals with acquired brain injury want to spend travelling to a service?***

In line with the previous point, older people were not happy to drive for any longer than 30 minutes to get to a place.

*“I could manage half an hour’s driving, I’d be happy to do that, but I think it’s better for general people to have a minibus.”*

Younger people with acquired brain injury, on the other hand, were prepared to spend up to one hour door-to-door travelling to a service they felt was worth attending.

***Services for carers?***

While older people with acquired brain injury were keen to give their spouses some time to themselves while they were attending a service, they also felt that in case they did depend on their “other half” to drive them, they would want him/her to have something interesting to engage in, too, and there seemed to be a consensus that a coffee shop on site was the very least that should be offered for spouses.

Younger people with ABI (who were planning to attend the service independently), were not concerned about there being regular services/opportunities for carers.

***Respite?***

None of the potential service users with acquired brain injury expressed an interest in respite care, though carers felt there was an element of respite to their spouses being engaged somewhere without the need for their input.

*“And I think it would be good for the carers and all, ‘cause I mean if you went for a day, and you had a minibus that could take him away for a day...If he could go out for the day, I wouldn’t mind going out for the day without watching [husband all the time]. To know that he’d be away with people, doing something different...it would be great.”*

While they were not interested in respite services, several young participants felt that being able to stay there for a night or more would be advantageous, particularly if they had to travel from quite a distance.

*“You could, like, have a cabin or something at the back of the farm. You know, like, two ten bed roomed things, so for people who live out the road, so at least you could offer it to them to come up and maybe stop for a couple of days each week.”*

## People with multiple sclerosis and Parkinson's disease

People with multiple sclerosis (MS) and Parkinson's disease (PD) share a gradual deterioration in their health which, for many, results in a continuous downward trajectory of health, functional ability and quality of life. It was much more difficult to recruit people with MS and PD to this study than people with acquired brain injury, and those that chose to take part were quite reserved about what green rehabilitation may have to offer them. Their perspectives seemed to be informed by what they can't rather by what they can do, and it was difficult to get them to see the potential of a farm/land based environment to improve their well-being.

Interestingly, several expressed a preference of not meeting with other people with MS or PD, because they did not want to come face to face with how much their own health may deteriorate by seeing others further on in their disease progression, or because they did not want to listen to other people's health related complaints when they had so much to cope with, themselves.

While people with Parkinson's disease and multiple sclerosis have some views in common, their views and preferences are distinct enough to warrant separate reporting.

### Preferences of people with multiple sclerosis (MS)

#### *What kind of services do individuals with multiple sclerosis want?*

##### **They would like a client-centred service to consider them holistically**

Individuals with MS expressed frustration at their experiences of being considered in terms of their diagnosis, and at health care professionals looking at a single part of their body in isolation.

*"I'm only ever looked at as 'that bit', they don't look at the same thing...[they don't] take into account the rest of your being... I think that people need to look at individuals as a whole and not as a bit"*

They would like a service to consider them holistically; understanding them as a unique individual in the context of their wider life.

*"It's important to be treated holistically...it makes you feel human. Because otherwise you're like a lump of meat being dumped here or dumped there, it's just not right"*

Individuals with MS explained that despite sharing a diagnosis, they each experience a unique set of symptoms and have a unique set of needs. The potential service users



would value a service that recognises this and responds accordingly, by respecting each individual's ability, skills and pace requirements.

*“Everybody knows someone with MS... so they assume that I’m going to be like that person. They don’t understand that there’s like hundreds of thousands of people with MS... and hundreds of thousands of different ways that it affects a person... its different, and it will be different this evening and different tomorrow”*

It is also very important for this group of individuals to have their personal interests acknowledged, as their attendance at a service would be largely driven by the appeal of the activities on offer.

### **People with multiple sclerosis would like opportunities to explore their abilities, and demonstrate these at a service**

This group of potential service users explained that they have experienced a sense a loss, in terms of their ability and of a life they had planned.

*“When I first got diagnosed I spent two years sitting there feeling very sorry for myself because I was no longer able to do the things that I was planning on doing with my life”*

They feel that it is important for a service to focus on ability rather than disability, and to enable individuals who attend to celebrate their present capabilities. Individuals with MS feel that they are given little encouragement to recover or improve their skills.

*“People who have become injured through an accident...they seem to be encouraged to move forward. But with [MS]...I don’t feel I’ve been encouraged to move forward”*

They would value a service which provides an environment in which they are able to do and achieve; a setting which allows them to discover and develop new skills, interests and talents.

*“Making you feel able and part of it and useful. I mean I have battled for seven years, feeling that I’m useless and that I’ve got nothing to offer anymore. I am getting better about it, but I still feel useless and I think that’s the main thing that I’d want to get out of it [a farm service]. If I was doing something like this, is the feel that I’ve achieved something and I’m proud of what I’ve achieved”*

This group of potential service users feel that demonstrating their competence in front of others would help them rediscover their self-esteem and confidence. Like people with acquired brain injury, they are interested in progressing their cognitive, creative and physical abilities, and consider that doing so would provide an opportunity to overcome feelings of a ‘loss of purpose’ which they have experienced.

*"I want people to see what we're doing and say 'that's brilliant'...I want a pat on the back and to be told 'well done you're making the best out of [it]'. I want to be told that actually 'that's really good.'"*

### **People with multiple sclerosis do not want to attend a service exclusively for people with multiple sclerosis**

Understanding the potential service users lived experience of the progression of MS provides important grounding for this theme. The individuals described the progressive nature of their condition as a multi-staged journey of accepting their disability, and involving a series of emotional and physical changes.

*"So there's a mental journey that you have to do yourself, and at several stages had to take a mental step...you can't push people"*

The potential service users with MS were not actively driven to spend time with others who share the condition, largely because of the challenges associated with seeing individuals further along their journey.

*"You don't want to face your future... you know it's there, but you don't want to know how you're going to end up"*

Those individuals who are in the more advanced stages explained that they had once shared such feelings, however were now aware that others with MS may not wish to spend time with them.

*"I didn't want to know about the people in wheelchairs, I'd rather have kept away from them thank you...I was fine with that. But now I'm in a wheelchair and I'm thinking 'why did I think that I didn't want to know the people in wheelchairs?' That's why nobody will talk to me [now]"*

A service that understands MS but does not explicitly focus on the condition would be beneficial to this group of potential service users. However, long-term conditions charities highlighted the large number of isolated individuals with MS, who are not known to services and not in contact with charitable support networks, potentially because they do not wish to be so.

The individuals who took part in the research are open to sharing a service with individuals with a range of conditions, although they would prefer individuals to have a similar need base to themselves. They explained that attending a service alongside individuals from a wider range of client groups, such as those with a learning disability, may deter some individuals with MS from attending.

## **People with multiple sclerosis are interested in attending a service based on a land or farm environment**

Individuals with MS who took part in this research, expressed strong support for a service which is based on a farm or land environment. They consider such a setting to be ideal for hosting a range of activities, which could be meaningful to a large range of individuals regardless of their level of ability.

*[a service on a farm/land] “could be the opportunity where you could pull people in and say ‘right you can’t run a marathon anymore, but you can go outside and enjoy yourself”*

They raised the therapeutic benefits of being outdoors in the fresh air, and would value the opportunity to spend time in an environment which was alternate to their own homes.

*“Some people just want quiet time in a beautiful spot”*

Conversely, the group brought feedback from other individuals with MS to the discussion, who could not understand how a farm or land based service would be either relevant or suitable for them. Much of their concern centred on the physical nature of many of the tasks associated with such environments, which they did not feel motivated or able to participate in.

*“...with MS you are quite restricted on what you can do, and [you] do find it really tiring and they don’t want to be working on a farm. They think they’re going to be digging fields and mucking out. But there are people who do want to do that and would really enjoy it”*

Many of the potential service users expressed interest in being involved in the development of a service, rather than simply beginning to attend when it was fully completed.

*“Personally I would be quite happy to be involved from early on”*

The group also felt that their involvement would be crucial in ensuring a service was fully accessible to users with disabilities.

*“I think with the best intentions of everybody, if they don’t have disabilities they don’t always see...when you’ve got problems, you would think ‘you won’t get a wheelchair in there”*

### **People with multiple sclerosis would like a service to be fully accessible, without highlighting disability**

The potential service users who took part in the research had a clear vision that a service based on land or a farm, could be made fully accessible and had the ability to meet their needs.

Whilst the group acknowledge that adaptations and equipment would be required to allow accessibility, they would value a service that does not make a 'big thing' about disability or the service users need to use equipment.

*"...saying 'look we're gonna help you here' without making a big thing of it either, I don't want it to be a big thing"*

This group would value the opportunity to reach places that they feel are normally inaccessible to them.

*"All that sort of stuff [getting to the top of a field]...fabulous, cause it gives people the opportunity to get places they can't normally"*

They would greatly appreciate a service which has cross country equipment such as buggies or wheelchairs that they were able to use whilst there.

*"...if you could get hold of some posh but second hand scooters, so that you wouldn't damage your own"*

This group placed importance on the need for a rest area, which individuals were able to access whenever they needed to. They consider this an essential feature.

### **People with multiple sclerosis would like a service to provide opportunities to have contact with animals**

All of the potential service users would welcome the opportunity to spend time with animals at a service. They highlighted the challenges of pet ownership, and would value access to domestic animals that they were able to pet and look after at a service.

*"You could have a dog that somebody could talk for a walk from their scooter. I mean it's not easy having a pet when you've got a disability. But it means they get the pleasure without all the blooming hassle"*

There was interest in having horses at a service, which were available to groom and take for short rides. The benefits of having contact with animals were described as multi-sensory; potential service users were drawn to the feel and smell of animals.

*"...just to go and feel a horse or do a little bit of grooming, or just a tiny bit of mucking out as long as it was in my capabilities...just to get that smell back, you know"*

The individuals do not want to be involved in long periods of physical work, due to their levels of fatigue and physical abilities.

### **People with multiple sclerosis expect a service to offer a choice of interesting activities**

Potential service users with MS consider that having opportunity to take part in a range of activities would have multi-faceted benefits. For example, engaging in activity alongside others, was viewed as an opportunity to socialise in an indirect, unthreatening way.

*“...you can make friends, you’re doing things with other people, you’re both focused on what’s in front of you, you’re not sitting eyeball to eyeball trying to size each other up all the time. You’re actually focusing on something else and I think that, seems to me, a very good way of getting people to know each other as easily as possible”*

Opportunities to create and explore, provide potential for a sense of ownership and expression. Having opportunity to sell on what you have produced was considered a good opportunity to develop a sense of purpose.

This group have a preference for engaging in a range of activities, such as rural crafts, growing vegetables seasonally and petting animals. Having choice over what to engage in is important for this group, to ensure that they are engaged in activities that fulfil their own personal need and interest base.

### **How much would individuals with multiple sclerosis be prepared to pay to attend a service?**

Those individuals who were in receipt of a personal budget and had control over its allocation, stated they would consider spending it on a service based on a land or farm environment if they felt it met their needs.

[would spend personal budget on farm service] *“...if at the end of it...I want to get something out being involved of it, either the feeling of or to take home my basket”*

A few individuals felt that they would be prepared to pay between £20 and £30 per session, if they felt that attending a service was beneficial to their wellbeing.

*“If it’s going to cost you £20 or £25 each week, then so be it”*

This group of potential service users are active consumers and if they were required to pay for a service, would expect it to be high quality and provide good value for money.

***How often would individuals with multiple sclerosis wish to access a service, and when would they like to do so?***

The group of potential service users viewed their need for a service as complimentary rather than core to their current lives; as such their attendance would reflect this.

*“It’s probably going to sound horrible and callous, but people with illnesses that don’t...they probably need the services more often than those of us that are lucky enough to say ‘we can come once a month’ because we’ve got time”*

They would like to attend once or twice a month, and would like to attend for half days due to concerns over their level of fatigue. They require a service to be flexible, allowing service users to attend when they wished rather than being ‘tied down’ to set days. Some of the individuals do not currently attend suitable services, because they do not allow such flexibility.

Individuals with MS would also like the freedom to arrive at and leave a service freely, rather than being fixed to set hours of attendance. A lack of flexibility in this respect may lead to them not attending a service.

*“It’s not something that I’m going to be able to say ‘I can do two hours’, cause I might be able to do five hours one day, and another I only might be able to do two”*

Their attendance would be driven by interest in the activities on offer, and there was interest in having a rolling events programme that they were able to view and select from in advance.

The potential service users acknowledged that there is a need for a service to offer ‘day care’, particularly for individuals in the more advanced stages of their condition. However, they associate negative connotations with the term ‘day care’ and may be deterred from attending a service which was explicitly labelled as such.

*“The word day care...urgh I hate that word, when they said ‘oh you need day centre money’...you know, you have this image of day centres with them just sitting there, playing bingo”*

***Access: How would individuals with multiple sclerosis like to travel to a service?***

All of the individuals with MS explained that transport to services in Northumberland, is a major issue and current challenge for them.

*“There are a lot of services that a lot of people like, it’s just travelling and getting there”*

Most individuals are reliant on travelling by car; largely with the assistance of their carer or partner. Some would prefer to access a service in this way, in which case they would require provisions at a service for their carer: this will be discussed further.

Others would prefer an opportunity to access a service independently of their partner on occasions, and suggested that a service offer individuals transport to and from the venue.

*“But I would like sometimes to be taken somewhere by somebody else”*

Although all individuals felt that independently accessing a service would be of value, they also expressed concern about being fully reliant on service transport. Their concerns were around an inability to leave as they desired and the potential of feeling stuck there.

*[on minibus transport] “The downside for me would be, what happens when I’ve had enough?...I can’t go. I have to wait for the bus...I have an illness that just hits you...and if you’ve got to sit around and wait for the bus, that’s hard”*

### **Access: How long would individuals with multiple sclerosis want to spend travelling to a service?**

Potential service users with MS would like to travel a maximum of 20 miles to a service. They explained that travelling long distances increased their levels of stress and fatigue, something they currently experience when accessing services and health care across Northumberland.

### **Services for carers?**

Individuals with MS were divided on this issue. Many would find enormous value in being able to access a service that they enjoyed without their carer, as feel it would be a way of regain some of the independence that they feel they have lost during the progression of their condition. Others would value attending alongside their partner, due to a practical and emotional reliance on them. In this case, they would like a service to offer activities for their partner or carer to engage in.

*“...we are holding on to our independence here, and as soon as we’ve lost a little bit of independence...but then again, if I went on [the mini bus], I’d be away from [carer] and I depend on him totally”*

Individuals with MS described the impact that their condition has on their partner, children and wider family.

*“...lives have been falling apart, partners leave...things like that happen. Because it’s a rebuild of somebody’s life and it affects a number of people...perhaps children”*

Many would value a service that offers opportunities to take part in activities as a whole family, and consider that this could be an opportunity for healing and also to demonstrate their abilities in front of others.



*“If it [farm service] could be open to carers...families fall to bits, and actually too...I’ve been thinking about me, I haven’t been thinking about my family”*

*“I just think that part of it is just helping that family rebuild, and I think that is a really great aspect”*

### **Respite?**

None required.

## **Preferences of people with Parkinson’s disease (PD)**

### ***What kind of services do individuals with Parkinson’s disease want?***

#### **They would like their services to be person-centred:**

This group of potential service users would like services to consider them as unique individuals, and respect their personal interests, skills and talents. They would like to be considered holistically, and to be viewed as a person rather than a diagnosis.

*“I really feel you that you should treat the whole person. Respecting the individual”*

It is important that they feel services understand their own personal needs and challenges, such as fatigue levels and their physical ability. They would like services to be responsive to these needs. For example, by providing a rest room with reclining chairs and beds to accommodate a need to rest during the early afternoons.

#### **People with Parkinson’s disease would like services to provide opportunities to experience aim and purpose**

Potential service users with Parkinson’s disease would be motivated to attend a service that provides them with opportunities to experience as sense of purpose. Suggesting that this could be enabled through allowing service users to set and work towards personal aims and goals.

They would like activities offered at a service to be purposeful. Examples of this are, by growing vegetables which are then cooked and consumed, or by craft activity with opportunity to sell what you have created.

*“I have a fear of knitting dishcloths...somewhere to sell the stuff, so it would have a purpose and people would feel useful. I’d be happy for something I made to be sold, the profits could be put back into the service”*



Describing previous experiences of some services as being a 'holding ground', with nothing to do. Their need for services to allow opportunity for a sense of purpose was grounded in feeling a loss of purpose as they were no longer able to work.

*"Purpose is important...I think it's important for people to have something to aim for. I'm feeling bereavement over the loss of a job...that your working life is over and the next step is death really"*

### **People with Parkinson's disease would like a service for individuals with a range of conditions**

Individuals with the progressive condition of Parkinson's disease described the challenges experienced in mixing with others who were at different stages of the same condition. They do not wish to be reminded of what may lay ahead for them, an experience they describe as 'frustrating and frightening'. They explained that this has acted as a barrier in the past, and they have not attended services because of it.

They suggest that by attending a service alongside individuals with different physical conditions to their own, as well as individuals with Parkinson's disease, may be beneficial. They feel that this may reduce the focus on their condition, and lessen the impact of their fears.

*"I didn't want to see what I'd become...I know that several people won't go to [charity] meetings because of that. It's frustrating and frightening really...so a cross range of physical conditions would be quite useful in stopping that".*

They are, however, initially resistant to sharing a service with wider client groups, such as individuals with mental health problems or learning disabilities.

Younger individuals would also like the opportunity to mix with others of their own age group, particularly as they described Parkinson's disease as being associated with older ages than their own.

### **People with Parkinson's disease would like a green-rehabilitation service, using a social enterprise model**

There was a keen interest and support for attending a service which is based on a farm or land environment. Potential service users would like such a service to be modelled as a functioning business i.e. producing to sell or give away. They would like this to be led by professionals, with opportunities for service users to feed into this, and would like profits to be put back into the service.

Individuals with Parkinson's disease would like a service to be integrated into the community with good links to charities and other services in the area. They see this as an opportunity to 'give back' and were drawn to the 'inclusive' feel that they feel this would provide. They would also welcome a service that was used by the wider public, who might visit the on-shop or attend courses.

### **People with Parkinson's disease would like the opportunity to interact with animals**

Contact with animals was identified as therapeutic, though service users would prefer this contact to be in terms of 'petting' animals rather than being involved in 'animal care'.

*"I don't fancy mucking out; particularly cause its heavy physical work. I think I'd prefer petting [animals]"*

Potential service users would like opportunity to use animal products such as their wool or milk, as the basis for creating products to sell on such as knitwear or cheese. They would value the opportunity to be involved in each stage of these processes, and gain the knowledge and skills associated with such activities.

### **People with Parkinson's disease would like the opportunity to learn arts and crafts skills to a high level**

Individuals would be motivated to attend a service that offered opportunities to explore a range of art and craft activities.

They would like to focus on their own personal skill development and would require the opportunity to learn skills to a high standard, progressing at their own pace.

*"I think as long as you have an opportunity to develop each person's gift in a way that they want to develop, that's the key thing really".*

The quality of the activities on offer is crucial and a lack of quality would prevent attendance. They would like to attend courses led by experienced professionals, and would be happy for these to be co-attended by members of the wider public. If they were skilled in a particular activity/craft, they would be happy to skill share with other service users on occasions.

### **How much would individuals with Parkinson's disease be prepared to pay to attend a service?**

They would not wish to pay for regular 'day to day' attendance at a service. However, they would be prepared to pay for attending 'professional' craft courses, where they were able to learn new crafts to a high standard. For such activities, they are prepared

to pay the full associated rate. However, it was clear that they are consumer-driven and would demand very high quality teaching and facilities for this.

***How often would individuals with Parkinson's disease wish to access a service, and when would they like to do so?***

For service users with Parkinson's disease services should be flexible and allow individuals to attend as and when they want to. There was concern that regular attendance i.e. on regular days every week may become stale and boring. Their motivation to attend a service would be driven by their level of interest in the particular activities on offer at any given time. For regular attendance to occur, activities would have to be of interest to them, and those activities would have to be kept fresh and updated regularly. They proposed a model where they were able to consider in advance what was on offer, and make a decision to attend based on this. A 'know before you go' approach.

*"It depends what's on offer, I think I would prefer to react to what's on offer. I would be interested in attending regularly if there were things I wanted to do"*

***Access: How would individuals with Parkinson's disease like to travel to a service?***

Potential service users expressed a preference for attending a service independently from their carer or partner. As they are reliant on their partner when travelling by car, they would prefer to travel independently using public transport. To enable this, individuals would require a service to be on a good bus route and be a short distance from the bus stop. Alternatively they would be happy for a service to provide a pick up from a bus stop.

*"Another barrier for me may be getting off at a bus stop and having to walk to the service. I'd have to have a pickup"*

If the service was not accessible by public transport they would attend by getting a lift from their carer, though this may impact upon the regularity of their attendance as they would have to factor in their carer's availability. If reliant on transport from carers, individuals would want a service to offer opportunities for their carers to engage in, too. They feel that their carers would wish activities, too. Suggestions of a café and high quality courses were discussed, this is addressed further in the carers section.

***Access: How long would individuals with Parkinson's disease want to spend travelling to a service?***

If using public transport this group would be prepared to spend up to one hour commuting door to door, though would prefer to less time in transit as were concerned about fatigue and the availability of toilets on long journeys.

***Services for carers?***

If fully reliant on their carer to transport them to a service, potential service users would require activities to be put on for their carers. These activities would need to be of high quality and of interest to the carers. Although individuals would prefer to attend independently, in which case would not require services for carers.

***Respite?***

Potential services users feel that if they attend services independently, their partners and carers would experience periods of respite during these times. They feel that if carers know that the individuals are engaged in activities they are enjoying at a service, they are motivated to attend; this would be a quality period of respite.

*"...helping people get out of their own environment and give carers respite. I think that'd be an area that is crucial"*

## People with mental health (MH) problems

Mental health disorders include, but are not exclusive to anxiety disorder, bipolar disorder, depression, eating disorders (such as anorexia nervosa or bulimia), obsessive-compulsive disorder, personality disorder, schizophrenia, social anxiety disorder and work related stress

The majority of people in the UK tend to be affected by them at least once in their lives, either personally, or via another family member or friend. Mental health problems account for as much disability in the UK as physical health problems. Despite this, a lack of understanding in the public and the media means that mental health problems often have a stigma attached to them. Many people affected by mental illness are, therefore, reluctant to seek help and many suffer social isolation.

## Preferences of people with mental health problems

### ***What kind of services do individuals with mental health problems want?***

**They would like the opportunity to socialise with a range of others, in small groups.**

Having opportunities to socialise at a service is very important for this group of potential service users. Many expressed feelings of loneliness and placed value on being able to meet new people, interact and potentially make new friends.

*“Key is the company...’cause I’m very lonely”*

Whilst they recognised benefits of mixing with individuals with similar experiences, they also felt judged and labelled when grouped under the category of mental health.

*“I’ve got depression and unfortunately it’s under the title ‘mental health’ and if people hear that they’re like ‘keep away from them, they’re crazy folk’. I don’t consider myself crazy or an idiot, it’s the word ‘mental health’”*

There was little preference as to ‘whom’ they would like to attend alongside, rather a drive to meet new individuals regardless of their background. There was some explicit support for attending a service with individuals with a range of conditions, and some individuals felt there was potential for them to learn and grow from such an experience.

*“If it’s a mixed group, I think they click in better. You get people in then that can understand somebody else’s problems, rather than just their own”*

Most individuals felt that such an approach would break down barriers of disability and create an atmosphere of social inclusion; something that they would like to experience. This group felt that social interaction was itself therapeutic.

*“To be able to get on and interact with people would be very therapeutic in itself”*

Potential service users with mental health problems also expressed a strong preference for mixing and working in small groups. Larger groups were perceived as less friendly and could lead to individuals feeling overwhelmed and unwelcome. The potential service users would also like the opportunity to spend time by themselves at a service whenever they felt it necessary, so would need a service to respect this.

Many of the potential service with mental health problems users would like opportunities to mix with individuals of their own age, and some feel that a service for all ages would be a good approach. Many would be put off attending a service if they did not know anyone there ahead of their first day.

### **People with mental health problems would like welcoming, understanding and supportive staff to create a relaxed atmosphere at a service**

The potential service users with mental health problems stated that they would not wish to attend a service where they did not feel welcome and comfortable. They would like a service to have a relaxed and welcoming atmosphere, and feel that staff are key to achieving this.

*“The most important thing is a friendly atmosphere...if you didn’t feel welcome...you’d think twice about going”*

The individuals would like staff to know, and genuinely care for them, personally.

*“If they [the staff] were really meaning to help you or they were trying their darndest to help you, that would keep me coming”*

They feel that staff at a service should have a knowledge and understanding of the issues associated with mental health problems, and to offer encouragement and emotional support in accordance with this. They have a clear view that service staff should be open-minded, accepting and empathetic, and this would lead to an appropriate atmosphere.

*“Nice staff, people who empathise and don’t judge you”*

These potential service users have previously experienced feeling unsupported at services, and this has prevented them from attending.

*“If they just left you to get on with it, that would put me off completely”*

They would like to feel that staff are available to provide support at all time, whilst having enough freedom and space to prevent an atmosphere of pressure. Such a relaxed yet supportive atmosphere is considered crucial to maintaining regular attendance

*"Its knowing someone is there if you need them, but they're not breathing down your neck".*

A clear hierarchical structure at a service would prevent these potential service users from attending. A number of individuals expressed that a service with a dominant boss figure would be the greatest barrier to attending.

*"The boss might put me off...having a boss. If he's gonna be a right picky sort. I'd want it to be relaxed, flexible...or I wouldn't go'.*

### **People with mental health problems would like a client-centred service where their views are respected**

All the potential service users with mental health problems would like a service to view them as unique individuals, rather than as a product of their diagnosis.

*"Cause everyone is so different in the world, no two persons are identical...not even identical twins. There's always a difference"*

They expressed a strong need for their individual interests, skills and abilities to be understood and responded to, including a service suggesting activities that they feel an individual may be good at.

*"You've got to think of the individual and ask the people what they want"*

*"To feel that support and encouragement. Someone saying 'I think that would suit you', that would be great"*

These potential service users would like choice and autonomy over what activities they engage in, fearing a service culture of being 'told what to do'. They would like to be engaged in activities at their own pace, that they find personally meaningful. They would not attend a service where they feel continually compared to others.

*"To go at your own pace and be accepted that if you're useless at something and somebody else is fantastic, that you're not going to be demoted..."*

These individuals would also like to feel 'listened to' by a service, and would like an atmosphere where they are able to express their opinions and preferences, and feel both comfortable and respected in doing so.



## **People with mental health problems would like a service to facilitate opportunities to progress and achieve, whilst allowing opportunity to relax when necessary**

Individuals with mental health problems would like a service to provide them with opportunities to experience a sense of achievement. They are driven to experience feeling good at something, and feel that their current life situations do not facilitate this.

*“...because I’ve had such a lonely life and I just wanna achieve something before its too late. I want to do something in a subject I feel good at, or that I would get a bit of praise for...someone to give us a pat on the back and say ‘well done’. Does that sound too big headed?”*

They feel that acknowledgement of their achievements by both themselves and others would lead to greater self-esteem and confidence levels. This would provide a key motivator to attend a service.

*“Every time you’ve achieved something new and you know you’ve done it to the best of your abilities...that gives you more confidence within yourself”*

Potential service users with mental health problems would value a service approach that facilitates their progression in skills and interests. They would welcome opportunities to set and work towards personal goals, at a pace that is right for them.

Having regular feedback and encouragement is very important to this group; they feel is crucial to their ability to progress and would provide a large incentive for them to attend.

*“Encouragement goes a lot further than anything else, like telling you what to do...encouragement would make me try something”*

They would value the opportunity to gain qualifications and certificates, which could give them a sense of achievement. Some would also like a service to provide a potential stepping stone ahead of paid employment, by allowing them to build up their self-esteem, routine and motivation levels.

*“You need to bring up their motivation and self confidence so that they can get back to work...otherwise as soon as they start, they’ll get sacked. A place like this [farm/land based service] would help a great deal”*

Whilst progressing was very important to the majority of these individuals, they would also value a service that allowed them opportunities for relaxing and escaping their life worries and pressures. A relaxed atmosphere is very important for them.

*“I’d like to go and relax ‘cause it would take me away from the pressures that I have at the moment, my illness. But I’d also like to move forward too, to learn something”*

*“Even if one day you just wanted to wander round cause your mind was mixed up and you wanted to sort your mind out...not doing anything other than staring at chickens or something. That would help people”*



**People with mental health problems would like a service to provide a sense of purpose and that a land or farm based service would be able to facilitate this**

These potential service users feel that 'having a purpose' in life is important to their recovery from mental illness, but feel that they have currently limited opportunity to experience this.

The individuals who took part in the interviews and focus group felt that the activities associated with a service that was based on a farm or land environment would provide a range of suitable opportunities to experience a sense of purpose.

*"[A farm service] would let you have a purpose...that is the biggest plus for me. Cause at the moment I don't feel I have an aim or purpose, I'm not getting out of bed as I should...I'm just lying there. It doesn't do you any good whatsoever"*

They feel that attending such a service would provide them with a reason to get up in the morning and potentially a better quality of life. Through opportunities to experience purpose, many individuals felt that they would also experience hope for the future, which is closely associated with their ability to recover.

*"It would make a tremendous difference to my life, my quality of life would be better. The thought of it....oh, it would be a wonderful experience"*

They feel that there is currently a lack of services in Northumberland that they are able to and motivated to access, but believe they would be motivated to attend a land/farm based service if it was a reasonable distance away (discussed further shortly). These individuals rely on hearing about services from health and social care professionals, and feel that many individuals are unaware of services in the area.

A service based on land or a farm would satisfy a desire to be outdoors and in contact with nature, which is held by the majority of this group.

*"I like prefer it...working outside. Feeling more relaxed when I'm out. I feel more content outside".*

Some raised the benefits of this in counterbalancing some of the side effects of their medication.

*"I love fresh air, it always helps me to relax. After you've taken medication its always a good idea to get outdoors, 'cause my head's always cloudy"*

Most expressed some reservation to working outside in very bad weather, and feel that this may reduce their motivation to attend a service.

Some of these individuals would also be interested in being involved in the design and development of a service.

*"I think it'd be better starting from scratch. I'd like to be involved from the beginning".*

## **People with mental health problems would like to be engaged in activities they find interesting**

Individuals with mental health problems expressed that they would like a service to provide opportunities to be actively engaged in activities. The majority of those who took part in the study explained that they would not attend a service where individuals were sitting around and chatting.

*“The kind of thing I hate is to sit around drinking cups of coffee all day, gossiping or talking about trivialities”*

*“Not just sitting there like in an old peoples centre playing dominos or bingo...nah I want more than that, sorry. How can they insult you by throwing dominos at you on a table and expect you to enjoy yourself....there’s a lot of people who say the same”*

This group would like a service to offer a range of activities, feeling that this would prevent feelings of boredom when attending a service. They would value the opportunity to explore new interests and skills.

*“you need variety, otherwise it gets boring and monotonous”*

They associated keeping active and ‘using their hands’ with being important to their recovery, as it would not only allow them to take their mind off other problems, but feel that by initiating ‘doing’ at a service, they would gradually become more motivated in all areas of their lives.

This group all highlighted their low levels of motivation associated with mental illness, so having a keen interest in an activity on offer at a service would be crucial to their motivation to attend. Whilst all of the potential service users hold unique interests, a service offering opportunities in a mix of animal care, horticulture and art/craft activities, would cater for the primary motivations of all those individuals we spoke to. Some individuals would like the opportunity to use and sell what they have grown through horticulture, made through craftwork or produced from animals. They felt that this would add to their sense of pride and achievement. However some expressed a preference to take things they had produced or created home with them.

### **(i) Animal care:**

The potential service users would like opportunity to spend time with animals, an activity which they consider to be therapeutic. All would prefer a service homing animals to be a petted rather than meat producing farm, though some would attend regardless of this.

*“The idea of setting up a farm with animals, which are excellent for rehabilitation, sounds absolutely lovely...right up my street, cause I love animals and to work with them would be very therapeutic”*

The potential service users would like a range of animals at a service, though some felt that larger animals such as cows or horses could be intimidating but would still attend a service where these animals were. Many expressed a desire to care for and pet smaller animals, an activity which they feel would be therapeutic and relaxing. They also value the purpose that looking after animals would provide, but some potential service users expressed that they would not like to feel fully responsible for the animals as this may exacerbate feelings of stress and worry.

*"[having responsibility] could be an added stress. Would have to be something that you weren't tied to or 100% responsible for...it could be a worry rather than an escape, you don't want to create another demon".*

(ii) Horticulture:

Some of the potential service users felt that gardening and horticulture would be therapeutic. There was a preference for light gardening and pottering rather than large scale manually focused activity. Whilst gardening would be the primary motivator to attend a service for some, the majority of service users we spoke to may be less motivated to attend a service where gardening was the only activity.

(iii) Art and craft activities:

There was interest in opportunity to engage in a range of craft activities. Interest was both in rural crafts and skills such as dry stone walling, and also in engagement in creative and expressive art and crafts such as art lessons, pottery and paper mache. These were associated with opportunities to develop creative skills and allow increased confidence through 'creating' something.

***How much would individuals with mental health problems be prepared to pay to attend a service?***

All of the potential mental health service users stated that they would not pay to attend a service; this was largely due to a low level of disposable income. At the time of their interviews and focus groups, none of the individuals had any knowledge of personal budgets or direct payments. However, they expressed that if they were in control of funds associated with their care, they would consider allocating this to a service based on a farm or land environment, so long as they enjoyed and gained value from attending, and it was situated locally to them. They feel that if a service did not deliver what it offered to, they would cease attending.

***How often would potential service users with mental health problems wish to access a service, and when would they like this to be?***

Individuals recovering from mental illness expressed a strong preference for attending half days at a service. They felt that spending full days would be too much, though some would like the opportunity to gradually build this up. Those that would like to attend half days would like to do so regularly: between 1 and 5 times every week. There was a strong preference for afternoon attendance, as mornings were explained as challenging due to symptoms of mental illness. It was felt that opportunity to attend in the afternoons would encourage a greater level of attendance.

One service user wished to attend on a 'drop in' basis, with a desire to visit a service for around half an hour at a time.

The majority of service users were driven to attend on regular days, and felt that this would lead to increased levels of confidence and an ability to schedule the rest of their lives around it. However, all would prefer some flexibility around attendance, so they were able to switch days when they needed too. Many would not attend a service that told them when they had to attend, as this would lead to feelings of pressure and feeling trapped which would be de-motivating to the individuals.

*"I wouldn't mind having set days to attend as long as they didn't say 'you've got to be here', cause then I wouldn't bother turning up"*

***Access: How would individuals with mental health problems like to travel to a service?***

The potential service users all felt that transport would be a big consideration, and would impact on their motivation to attend a service. All would prefer to walk a short distance to a service, rather than have to use public transport. However, if a service was something they were highly motivated to attend, they would consider accessing it by using a public bus. In this case, they would require the service to be located near a bus stop, with a regular service. They would also require the journey itself to be a reasonably short distance. The emotional challenges of travelling on public transport for long distances were raised by some of the potential service users.

*"It's extremely hard for people to get on a bus and go to a strange place, because of mental illness"*

Of those potential service users who do not have a free bus pass, being required to pay to travel on public transport would be a barrier to attending.

One service user was able to access a service by car if necessary. There was some interest in a service providing a minibus or other forms of free transport, but there were

some concerns expressed around this due to feeling like they would not be able to come and go freely if reliant on service transport.

***Access: How long would individuals with mental health problems want to spend travelling to a service?***

The potential service users with mental health problems have a strong preference for services to be very local to them. Ideally a service would be located around 5 minutes walk away; having a service further may reduce their motivation to attend. If a service generated a high level of interest in them, they would be prepared to travel between 20 – 30 minutes door to door, but felt that this would possibly impact on the regularity of their attendance.

*“I wouldn’t want it to be too far, cause the further it is away...the less likely it is that you’re gonna go to it”*

One service user would be prepared to travel up to an hour for a service, if it was felt that attending was satisfying a number of needs affectively.

***Services for carers?***

Those interviewed were not reliant on carers for independent living so did not require services for carers. One individual, however, expressed concern over the worry that their illness caused family and friends. They feel that giving carers and family opportunity to attend a service on occasions would allow them to see individuals with disabilities succeeding and this would be of great value.

*“If they [family] came to one of the activities, it might give them a chance to see how other people cope. To see me doing things...it might help them”*

***Respite?***

One potential service user would value the opportunity to attend a service for a short break, which would release their family from worry for a short period.

## People with learning disability (LD)

In 'Valuing People', the 2001 Government White Paper on the health and social care of people with learning disabilities, learning disability is defined as "the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development." [25].

There are around 1.5 million people in the UK who have a learning disability. Some of them have a medical disorder that is associated with learning disability, such as Down's syndrome which is apparent at birth. In others, it becomes apparent as they grow up, perhaps due to delays in language development. "Some people with a mild learning disability can talk easily and look after themselves, but take a bit longer than usual to learn new skills. Others may not be able to communicate at all and have more than one disability." [26].

### Preferences of people with a learning disability

#### *What kind of services do individuals with a learning disability want?*

#### **People with a learning disability would like opportunities to socialise through teamwork**

The potential service users with a learning disability that we spoke with, would like a service to provide opportunities to work collaboratively in small teams, on a range of projects. They would value this as an opportunity to meet other people and make new friends.

Socialising at a service is important to this group of individuals, but rather than attend a service for explicitly 'social reasons' they described a service that would allow socialising to be gained through working together, with a shared focus on the activity they were engaging in.

*"Socialising is important, cause then I would have other people to speak to...cause I like talking to people. I don't get much chance to do that now".*

All the participants enjoy meeting new people and would not be deterred from attending a service if they did not know anyone prior to their first visit. They described no preference for 'who' they attend a service alongside, and had no objections to sharing a service with a range of other client groups.

*"I'm not really bothered who goes, just be good to meet them. I would attend all the time, I'd be really motivated"*

### **People with a learning disability would like to attend a service that was based on a land or farm environment**

Potential service users with a learning disability would be highly motivated to attend a service which was set on a farm or land-based environment. They feel that such a service would satisfy a number of their needs, such as their desire to be outdoors and engage in activities that they are interested in, namely DIY and animal care.

*"I like being outside, I'd be happy spending all my time outside. I like doing stuff"*

Individuals would welcome the opportunity to be involved in the practical side of developing a service from scratch, as again it would allow opportunity to be engaged in practical and purposeful activity. They consider there to be no barriers that would prevent them from attending such a service, other than the ability to travel there and the costs associated with attending. Both of these factors are addressed shortly.

### **People with a learning disability would like to be involved in practical animal care**

Individuals would like the opportunity to be involved in the practical side of animal care, rather than simply interacting with animals through 'petting'. They described a desire to engage in physical activities such as grooming and feeding, preferring to take a 'hands on' approach at a service.

The individuals interviewed were driven to hold additional responsibilities, and see animal care as a suitable way to achieve this. They feel that having opportunity to take on responsibilities would increase both their levels of happiness and confidence.

*"I love working with them [animals]. I'd like to do it now. If I could do it now it would make me more confident. It made me confident when I worked with them"*

The potential service users would like a service to include a wide range of animals, from chickens and ducks, through to horses. They expressed limited interest in riding the horses themselves, preferring to be involved in the grooming and feeding.



### **People with a learning disability would like opportunities to be engaged, and to achieve, in practical activities**

The potential service users interviewed were driven to be 'occupied'. They would like a service to provide opportunities to be engaged in a range of activities, preventing them from being 'stuck indoors'.

They are interested in being involved in practical activities where they are able to 'use their hands'. The participants would like such activity to be purposeful, and enable them to experience a sense of achievement through creating or helping. They are interested in a range of activities, however were particularly motivated by DIY/woodwork, horticulture and animal care.

*"I wanna do practical stuff, with my hands"*

### **People with a learning disability would like opportunities to explore new interests, and develop new skills and knowledge**

The potential service users would like a service to provide opportunities to explore new activities and discover new interests. They would like to feel that attendance has a focus on progression, with a goal orientated approach.

Learning new skills and gain new knowledge is very important to this group.

Having the opportunity to work towards and gain certificates and qualifications is also very important. They would like a service to provide a grounding to their next step in life e.g. paid employment.

*"Getting a certificate makes us feel like I've done something, like all the work I've done is for something. It's important to me"*

### **How much would individuals with a learning disability be prepared to pay to attend a service?**

Individuals did not want to pay to attend a service. No participants had knowledge of direct payments or personal budgets. Though all stated that if they were given control over how a budget was spent on their care, they would want it to be spent on a green rehabilitation/care farming type service, as feel it would be capable of meeting their needs.



***How often would individuals with a learning disability wish to access a service, and when would they like this to be?***

Potential service users would like to attend a green care/social farming service regularly: between two and five days every week. They would like to attend on set days, which were consistent from week to week. The individuals we spoke with were driven for consistency and routine.

Attending such a service would be initially motivated by an interest in the activities available, particularly contact with animals, DIY/woodwork opportunities and horticulture. They would wish to continue attending a service, as long as these or other activities of interest were available to them.

The potential service users would like a service to offer opportunity to attend on an ongoing and long term basis, rather than attending for short or limited periods.

*“I’d like to go as often as I can, I’d like to go every day. Cause that dry stone walling course, I went every day and then it just stopped and I was gutted as I just wanted to keep doing it and that. Cause I knew I was doing it every day, cause I was getting up, getting ready and going there. The routine was good”.*

***Access: How would individuals with a learning disability like to travel to a service?***

The potential service users would be reliant on public transport to travel to a service. They are happy to travel in this way, but stressed their need to have a service that is accessible on a bus route. Alternatively they would be willing to travel to a designated pick up point on public transport, if the service was able to collect them and transport them for the remainder of the journey.

The availability of transport is crucial to enable their attendance. A lack of suitable public transport currently acts as a barrier to attending a number of suitable services that the participants would otherwise be motivated to attend.

*“Transport there and back would be the most important thing, it could be a problem if I couldn’t get the bus there”*

The individuals we spoke with all have access to a free bus pass, which would allow them to travel via public transport for free. Whilst this cannot be generalised to the whole of the client group, cost of transport would not be a barrier to attending if they were able to travel by bus. Using other modes of transport that would involve additional costs (e.g. taxi or train) would prevent the participants from attending.

***Access: How long would individuals with a learning disability want to spend travelling to a service?***

The individuals in this service user group were highly motivated to attend a land or farm based service, and this was reflected in their willingness to spend more time travelling there, than many of the other groups. Potential service users were willing to travel a maximum of 1 ½ hours each way, from leaving their door to arriving at the door

***Services for carers?***

No services for carers are required.

***Respite?***

Nobody in the group expressed an interest in respite services.

## Findings Commissioners

We undertook this market research at a time of considerable change in health and social care administration, including commissioning of services. Commissioning of health care services is moving countrywide from the current Primary Care Trusts to Clinical Commissioning Groups [27]. There will be one Northumberland Clinical Commissioning Group (NCCG) to which 49 GP surgeries across Northumberland will contribute. At the time of data collection the structure of the new NCCG was emerging and so were roles of commissioners (different GPs will take the lead in commissioning services for specific patient groups, such as people with neurological conditions, diabetes, mental health problems, etc.). This was a very busy time for the new NCCG, including its commissioning leads, and as a result, commissioners relevant to our study were not available to meet.

However, we were able to meet up with Ann Brown, Valuing People Coordinator at Northumberland Healthcare Foundation Trust. She expressed an interest in the use of land-/farm-based environments for the care and rehabilitation/enablement of people with learning disability. She also suggested that it would be advantageous for providers to have day service accreditation, and that she is looking to find extended work placements for people with learning disability that allow service users to experience progression (something also called for by potential service users with acquired brain injury). Ann said explicitly that she wanted to see “the development of ethical, high quality personalised services which offer purposeful activity, showing evidence of individualised learning and progress, integration and contribution to local community, with positive benefits to mental and physical wellbeing. The latter could be a range of things from improvement of mood states and self-esteem to maintenance/improvement of physical health”.

This statement pretty much encapsulates what potential service users wanted from a service, and we are encouraged to see that there is such agreement between service users and this service commissioner on the ethos and purpose of a reablement service.

## Summary of findings across the client groups

Each individual who took part in this research described a unique set of interests, needs and preferences. However, distinct themes of thought emerged between the individuals within each of the client groups. These emergent themes have been discussed in turn earlier in this report. There were also a number of commonalities between the views and preferences expressed across different client groups; these reflect shared preferences amongst individuals regardless of their background, needs or condition. These common themes across groups are reported below.

### Services based on land or farm environments

A key question at the basis of this research study was whether a land-/farm-based environment can meet the rehabilitation and/or social care needs of potential service users. All but a small number of individuals who took part in this research felt that they would be interested in attending a service which was based on land or a farm, and believe that such a service would have the potential to meet at least some of their individual care and rehabilitation needs. Many who took part in the focus groups and interviews, entered the research process with an understanding of how activities they assume would be on offer at a green rehabilitation or social farming service, could be of benefit to their health and wellbeing. For these individuals, the data collection process served as a channel to creatively explore the concept further and many reported feeling increased confidence in the breadth and depth of potential impact that a green rehabilitation or social farming service could have.

Some of the individuals who took part in the research entered the process with a level of uncertainty about how a service based on a farm or land could be of benefit to their recovery or care. However, by the end of their focus group or interview, all reported that they now had a belief in the potential of green rehabilitation or social farming, even if they were not personally interested in attending a service of this kind.

Many of the participants and charity partners involved in this research fed back to the researcher that a number of individuals who did not wish to take part, declined because they did not feel that a service based on land or a farm setting could be appropriate to them. This feedback fell largely around individuals with long-term conditions, and referred to individuals' association of 'farms' as environments for very physical activity, something that they did not feel able to, or potentially motivated to, engage in.

## **Demand for client-centred services**

A theme that was expressed very strongly across client groups, and a criterion for attendance that weighed more heavily than anything else, was the demand for a person-centred service. Potential service users would like services to consider them as unique individuals, both in terms of respecting their personal interests and preferences, and in understanding their individual challenges and abilities. This was explicit in the discussions of each of the client groups, except in those of individuals with a learning disability (where it was implicit).

## **Ability to socialise at a service**

Socialising at a service held varying degrees of importance to the different groups. Individuals with mental health difficulties and individuals with an acquired brain injury explained that having opportunity to socialise with others at a service was of high importance to them; individuals with learning disabilities also felt that socialising at a service was important, but preferred to do so in a non-direct way. The opportunity to mix with others with shared experiences was particularly important to those who have experienced a traumatic brain injury, who felt that doing so helped to address the physical and emotional isolation they experienced following their brain injury.

Individuals with mental health problems, learning disabilities and acquired brain injuries all felt that a service open to and accessed by all client groups would be beneficial, expressing a desire to learn from and help each other.

Although individuals with multiple sclerosis and Parkinson's disease acknowledged the potential social benefits that could be gained from attending a service, having opportunity to socialise would not be a fundamental motivation for them to attend. Individuals with Parkinson's disease and multiple sclerosis, both progressive conditions, were not driven to mix with others with the same condition as they feel it would make them focus on to the journey of their condition that may lay ahead. Both of these groups would welcome a service shared with others with varying physical conditions, but both were hesitant about sharing a service with individuals from wider client groups.

All of the client groups who took part in the research had a preference for an "indirect" approach to socialising: they expressed a dislike of "sitting around, chatting" and felt that working alongside others on a project or activity would be a good route to achieving social interaction with others. There was a strong preference for working in small groups, and the concept of working in larger groups was viewed as less welcoming and potentially threatening to individuals.

## **The activities offered at a service have to be interesting**

All of the groups expressed a preference for engaging in activities which they found personally interesting. Although interest was unique to each person, the majority of individuals had interest in at least one of the three activities which were most closely associated with a service based on land or a farm: horticulture, animal care, woodwork/crafts. All of the groups would like a service to offer a range of activities, providing them with opportunity to explore and develop new interests and skills.

Each of the client groups felt that spending time with animals had the potential to be therapeutic, and many individuals expressed explicitly that they felt that it would be beneficial to their wellbeing. Some explained that they currently have limited opportunities for contact with animals, and would welcome a service that enabled this.

## **The opportunity to experience achievement and progression**

Individuals from each of the client groups would like a service to offer opportunities for them to progress and achieve. Whilst the direction and context of such progression and achievement was unique to each individual, all were united in a fundamental wish for an environment to demonstrate and build upon their personal abilities.

## **Paying to attend a service**

The majority of the individuals who took part in this research would not wish to pay to attend a service. This was true of those with traumatic acquired brain injury, mental health problems and learning disabilities, and was based on a lack of funds to allocate to a service at this stage of their lives. Individuals with multiple sclerosis and Parkinson's disease, and a small number of individuals with stroke would not wish to pay to attend a service as standard. However, they would be prepared to pay for a high quality service which was substantially positively impacting on their wellbeing, or for a course in a skill (arts/crafts) that was delivered well by a specialist in this field.

Individuals from all client groups would consider allocating their personal budget for health or social care to a service based on a farm or land if they had control of this. In such a situation, they would be increasingly consumer driven and demand a high level of quality and impact.

## **Travel and transport as a barrier to attending**

The challenges of getting to and from a service were explained as the biggest barrier which would prevent attendance. This was true of all of the client groups and was described as a current challenge experienced by individuals living in Northumberland.

While the time that each of the client groups would be prepared to spend travelling to and from a service differed a great deal, individuals were united in the fact that they would not travel to a service beyond their preferred distance on a regular basis.

A large number of individuals across all of the client groups explained that they were fully reliant on public transport to access a service. For these individuals a service would need to be set on a route accessed by regular public transport, or alternatively the land-/ farm-based service would need to provide transport itself.

## Discussion

### Very individual needs

From the focus group discussions and interviews it was apparent that potential service users' needs and aspirations are both complex and diverse. This is a challenge, in that the needs are diverse even within potential client groups/health backgrounds. For example, some people with acquired brain injury prefer regular breaks every 45 minutes, others expressed that they would need the opportunity (and facilities) to rest or even sleep when they need to, but prefer to stay engaged in an activity they are absorbed in while they feel alert, rather than have scheduled breaks.

While it should not be surprising that people with long-term health conditions are discerning customers of health and social care, their demand for high quality and stimulating activities, as well as the expectation of many to attend when it suits them and/or when particularly interesting activities are "on offer", rather than on fixed days and at fixed times or for specific durations of time, will require somewhat of a shift in expectation and practice on the part of service providers, as well as commissioners.

All potential service users involved in this study expressed a desire for a diverse range of activities and for stimulation; they also want a choice of different activities to engage in. Several expressed an interest in engaging in seasonal activities, or other activities that allow them to follow a product through its life cycle, such as the experience to first grow fruit and vegetables, then make them into a product, such as jams, chutneys or cakes, that can then be sold in a farm shop, or first shearing sheep and then carding and spinning the wool, before using it in textile crafts. In fact, these are cycles of activities that DD saw applied very successfully in social farming in Sweden during a Northumberland Uplands LEADER-supported study visit in 2010.

### Implications for service development and delivery

The diverse needs and preferences expressed by potential service users affect both what a green rehabilitation/green care service needs to offer its clients in terms of activities and facilities required, and who is likely to want to access the service and when.

While the discussions of implications for individual service development is beyond the scope of this project, it is clear that service users are discerning and only prepared to spend money on what they feel meets their needs and satisfies their interests. Therefore, for green rehabilitation/social farming service providers to be successful in



first attracting service users and then “keeping” them, they need to be careful to provide an environment and activities that meet their service users’ needs and preferences.

In line with recent changes to the funding of health and social care, individuals with long term health conditions across the UK (parts of the North East have been a pilot area for the implementation of this policy) will soon be awarded a lump sum (a “direct payment” or “personal budget”) each year, based on their special needs, which they can spend as they wish. In other words, commissioning and payment for services has moved from social services and the NHS to individuals with special needs. Particularly in view of the introduction of personal budgets, it is imperative that green care services provide the environment, activities and ethos potential service users are looking for.

Aside from the market force imperative for a person-centred service, the enthusiasm with which many potential service users contributed to this project, the excellent ideas they shared and their ability to make (health care!) professionals aware of what really mattered to them, shows that current and aspiring service providers ignore their (potential) service users’ expertise at their peril.

## Limitations of this study

We tried to recruit people with spinal cord injury (SCI) to this study. However, the feedback we received from a regional link person for people with SCI was that there wasn't a great demand for services, and no interest in taking part in the research. This, in a way, is a positive outcome, as it would seem to signal that people with SCI manage on the traditional rehabilitation services currently provided to them. In terms of green care, it would seem to indicate that this is not a client group service providers need to consider specifically, unless they have information to the contrary in their area.

Despite our efforts, we were able to recruit very few potential service users from very rural locations within Northumberland. This means that a considerable number of people for whom land/farm-based rehabilitation services may be both of interest and local to their place of residence did not have an input into this study and are not represented in its findings. While this is in itself regrettable, it also highlights a wider and important issue. As we accessed potential service users through organisations for and of people with long-term health conditions, this may indicate that people from remote rural areas are less likely to access and/or be involved in these organisations, and that therefore, their rehabilitation/reablement and social care needs are little known to those providing services for people with long term health conditions in rural Northumberland.

We are also concerned that we did not manage to get any input into this study from adults with cerebral palsy. While statistically they should make up a considerable number of people with long-term neurological conditions, they seem to be under- and

possibly un-represented within organisations for people with long-term neurological conditions. Sadly, this is not entirely surprising: Studies suggest that once individuals with cerebral palsy have made the transition from paediatric to adult services, they disappear off the map of social and health care providers, only to “resurface” many years later, often with severe complications which could have been avoided if appropriate on-going care had been provided [28-30]

This is worrying, as it is likely to suggest that their needs for rehabilitation/reablement, care and meaningful occupation go unrecognised and that they don’t have a voice in shaping the services they need. As a result, the Chartered Society of Physiotherapy made the transition from children’s to adult services of people with cerebral palsy a national research priority.

Within the time frame and budget of this study were also not able to recruit older people at risk of social exclusion to this study. This was because the very reason of why we wanted to include them makes them difficult to identify and engage with.

## Impact of this study

### Impact on the researcher

Kelly Heartshorne, MSc, MBAOT, the contracted researcher who undertook the majority of data collection and analysis, has found that her involvement in this project has given her an opportunity to further develop her qualitative research skills, in an area that she feels extremely passionate about. The feedback and guidance offered by the project manager (Dorothee Debusse) allowed her to develop and refine her skills at each stage of the research process. Importantly, Kelly feels that aspects of this project, such as engagement with individuals from a diverse range of health-related backgrounds and the experience to facilitate large group discussions, has carried over into and enriched her practice as an occupational therapist and her work as a researcher.

### Impact on participants

The timely involvement and inclusion of service users in service development is something that is called for by government recommendations, as it results in services that are meaningful for those they are intended for. This results in much better engagement of service users, and therefore, in better health outcomes and better quality of life.

While the majority of study participants may not experience any immediate benefits from taking part in this project, many expressed how pleased they were to be consulted on the development of services intended for them. It made them feel consulted and valued for the unique contribution they were able to make to this project. Feeling valued for what we give is important for anybody; it is particularly important for people who have lost so many of their roles and responsibilities.

Interestingly, by taking part in discussions about the potential benefits of interacting with animals in this study, a number of participants fed back that they were reminded of how much they enjoyed spending time with animals. A few have now made changes in their lives to facilitate this, and have since been in touch to let us know what a positive impact this has had.

## **Impact on services for people with long-term health conditions**

This report, and the more detailed paper on people with acquired brain injury which results from this project and will be submitted for publication in an international peer reviewed journal on rehabilitation, highlight important issues relevant to green care as well as more general, non-farm/land based rehabilitation and care services for people with long-term health conditions. This means that services for those clients can be reformed in view of the insights generated in this study.

## **Impact on social farming in Northumberland**

It is hoped that current and aspiring social farming providers and health/social care commissioners in Northumberland will use the findings from this study to inform the services they provide and commission, respectively. This report provides a unique and detailed insight into what services users want, how and where they want to access them, and how much they are prepared to pay for them. It should become the basis for very successful land/farm-based rehabilitation and care services for people with long-term health conditions in this county.

## **Impact on the wider social farming community in the UK and beyond**

While some of the issues raised in this report have particular relevance to service provision in Northumberland, many are likely to be shared by people with similar health problems in other parts of the UK and beyond.

For example, and paradoxically, accessing green care services within walking distance is likely to be much more realistic for people with mental health problems in urban areas who live close to “city farms” than people living in rural Northumberland. The evidence provided by this study will help “city farms” develop/reform services in line with potential service users’ preferences and needs, and help them argue for continued or improved funding of the services they provide.

To maximise the impact of this project, we will make this report available to Care Farming UK for the benefit of its members and partner organisations within the UK and beyond. We will also share this report with Ingrid Whitehead, the advisor on green care to the Swedish national farmers’ union, and to relevant green care provider and commissioner contacts we have in Sweden.

## **Impact in terms of evidence in this field**

As they are much longer than scientific articles published in peer-reviewed journals, reports of this kind are helpful in providing detailed information about a project and its findings, and therefore, an important means of informing policy and practice. We will publish this report on our website [www.horsepowerforability.com](http://www.horsepowerforability.com) which is regularly visited by, and results in enquiries from, people from all over the world.

Participants in this study provided unique insights not only into their preferences and aspirations in relation to green care/social farming services in Northumberland, but also into their own experiences of their disability and how they (learned to) cope with it, as well as of health and social care services.

People with acquired brain injury were particularly expressive on these issues. This, in combination with their explicit suggestions of activities, facilities and animals provided particularly “rich pickings” and food for thought. As a result, the findings from this study which are specific to people with acquired brain injury will be written up and submitted for publication in an international peer reviewed journal on rehabilitation. This will reach an international audience of specialists working in the area of care and rehabilitation for people affected by acquired brain injury and can, thus, inform practice well beyond the original scope of this project.

## Conclusion and Recommendations

Green care/social farming may offer an innovative, cost effective and meaningful alternative model for social and health care provision at a time of increasing cuts to traditional health and social care services. However, current and aspiring providers of green care in Northumberland were unable to engage in realistic business planning and the development of services, because of a lack of market research/firm figures that apply to potential service users in the local area.

The aim of this Northumberland Uplands LEADER-supported study was to explore whether and how a land/farm-based environment may meet the care and rehabilitation needs of people affected by long-term health conditions, to be able to establish the basis for realistic business planning across this sector in Northumberland.

We were able to engage with a wide range of individuals from a wide range of health backgrounds in Northumberland. The qualifications and experience of the researchers involved in this project, as well as their rigorous approach to data collection and analysis ensured the findings are trustworthy and likely to be transferable to a wider range of people with long-term health problems living in Northumberland than those who took part in this study. Importantly, study participants have explicit expectations of and preferences for the types of services they would like to receive/engage with.

Most participants were positive that a “green” care/rehabilitation setting can meet many of their rehabilitation needs and that this environment is likely to help them and others focus on their abilities, rather than their impairments. However, study participants across health backgrounds expressed a strong preference for a small-holding type of environment, as opposed to a commercial farm, and many expressed a reluctance to be involved in an operation that included the rearing of animals for slaughter. Importantly, there was overwhelming consensus amongst participants that a while a land-based environment offers attractive opportunities, it is secondary to their need for a person-centred specialist rehabilitation service.

Based on these findings and the expertise people with long-term health conditions can offer in the design and development of services, we urge current and aspiring green care service providers to involve potential service users closely in the development of new and the reform of existing services. The provision of care and rehabilitation is now a market economy, and providers will ignore the wishes of their clients at their cost.

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