D2.1. Self-management in Stroke

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<td>This report describes the risk factors for stroke; the current practice in the stroke pathway with regards to discharge decisions and what happens in the first 6 months; the current use of tele-rehabilitation and other technology in stroke. The report also suggests functional and non-functional requirements to enable self-management</td>
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Introduction

The overall goal of the STARR project is to provide an integrated self-management solution for people with stroke by bringing together experts in stroke, video analysis, physiological sensor monitoring, usability, lifestyle analysis, data fusion and platform development to work collaboratively with user communities and patient support organisations.

This is needed because stroke is the single largest cause of adult disability worldwide and this global burden is increasing. Rehabilitation and independence after stroke improves the ability of people to lead productive socioeconomic lives but these benefits are only partly translated from research into clinical practice. At one year after stroke approximately 30% of survivors remain dependent on others for basic everyday tasks e.g.: walking indoors, toileting and getting dressed. Between 60 and 80% are unable to walk in the community again and 31% have depression six months post-stroke. Such disabilities impact their ability to be employed and fulfill social roles and also place them at risk of subsequent stroke. The socioeconomic impact of all of this is enormous. In the EU each year, stroke costs approximately €27 billion. Another €11.1 billion is the cost of informal care. The majority of costs relate to rehabilitation and life after stroke and since a stroke can produce a variety of lesions in any part of the brain, the physical and psychological problems after stroke are diverse and not always evident immediately. Inter-disciplinary interventions should therefore be tailored for individuals and refined over time and this is a key recommendation for the STARR system.

Recovery also requires active participation by stroke survivors as re-connectivity of brain networks depends on practice of difficult functional tasks. Stroke survivors are unprepared by their pre-stroke healthcare experiences for making the immense effort to drive their recovery. So, therapists have to incorporate individualised behavior-change strategies into interventions and the aim of this project is to provide a home-based platform to do just that.

Stroke rehabilitation is mostly provided through Early Supported Discharge Services in Western Europe as most stroke survivors are in their own homes. Typically, stroke survivors see a specialist therapist once or twice a week for review of progress and intervention prescription and self-administer their rehabilitation prescription supported by visits from a therapy assistant (unqualified). Consequently, stroke survivors are not benefitting from a rehabilitation environment where: (i) specialists can identify clinical response quickly, (ii) specialist rehabilitation devices are available and (iii) where peer support is inherent to the rehabilitation environment. Indeed, stroke survivors often report feeling isolated and alone. Returning to in-patient based rehabilitation is not an option because of (a) cost and/or (b) population geography. A paradigm shift in rehabilitation provision via self-management is required urgently to enable stroke survivors to benefit from the latest evidenced-based rehabilitation interventions in their own homes.

This document will therefore report on several overlapping concepts relevant to the above context i.e. the common risk factors for stroke and how to advise on them; a typical stroke pathway; and the role of tele-rehabilitation and self-management in stroke. Finally, we suggest some top-level user requirements that technical partners must be aware of when interacting with stroke survivors. As throughout in WP2, the intention of this report and D2.2 is to inform those members of the STARR consortium with no prior experience of stroke about the context in which the project sits.
**Risk Factors**

A superset of risk factors was discussed in D2.2 and will not be repeated here. Instead, we will describe, in lay-terms, the most common risk factors.

Fig. 1 below shows a simple visual representation of modifiable and non-modifiable risk factors used by the Stroke Association in training events to lay audiences of stroke survivors and their carers.

![Risk Factors Diagram](image)

Figure 1. Patient friendly design representation of common stroke risk factors

The descriptions and tone in the following text are those used by the Stroke Association when it communicates stroke-related lifestyle risk to the general public. Hence, they are short, relatively non-medical and are in a form that can be directly embedded in the STARR system (for instance as tooltips).

For ease of reading, all of this section is written from a third person perspective, as if giving advice to a stroke survivor.

All advice is fully referenced by our Knowledge Management team at the Stroke Association and is peer reviewed by a panel of independent stroke experts. It is guaranteed to be understandable by the lay public with no knowledge of stroke, healthcare systems or the relevant epidemiological or science literature.

This text can thus be used verbatim within software components of the STARR project and embedded in help functions.

What increases your risk?

As we age, our arteries become harder and narrower. However, certain medical conditions and lifestyle factors can speed up the process and increase your risk of having a stroke. Medical problems like high blood
pressure, high cholesterol, atrial fibrillation (an irregular heartbeat) and diabetes can increase your risk of having a stroke. Lifestyle factors, such as diet, drinking alcohol, taking drugs, smoking, and how active you are, also affect your risk. Taking steps to change as many of the risk factors as you can will help you to reduce your risk of having a stroke.

### Modifiable risks

Modifiable risks are those things than can be changed by how you live your life.

#### Controlling medical conditions

A number of medical problems can increase your risk of having a stroke. Your doctor can test you for them and give you advice on how to control them.

**High blood pressure**

High blood pressure (also called hypertension) can damage your arteries. You may not know if you have high blood pressure, so you should have it checked regularly. The ideal blood pressure for a healthy adult is less than 120/80mmHg.

**High cholesterol**

Cholesterol is a type of fat produced by your liver. It is also found in foods like meat and dairy products. Your body needs small amounts of it, but too much is unhealthy. Extra cholesterol can travel around the arteries in your body, narrowing them and increasing your risk of stroke. You can lower your cholesterol by making sure your diet is healthy and low in saturated fats. Your doctor may advise you to take medication, too. If you are over 40, you should have your cholesterol checked regularly. It should be under 5mmol/L.

**Type 2 diabetes**

Diabetes is a condition where there is too much sugar in your blood. This can cause fatty deposits to build up in your arteries, which can lead to them becoming blocked. This then increases your risk of having a stroke, particularly if you have had diabetes for a long time and you have not been controlling it very well.

**Atrial fibrillation (a type of irregular heartbeat)**

When the heart beats irregularly, blood clots can form and travel to the brain. They can block an artery and cause a stroke. If you have atrial fibrillation, your risk of having a stroke is increased up to five times. You are more likely to develop this condition if you are over 65.

**Heart disease**

Other problems like heart valve disease and heart attacks can increase your risk of a stroke. Having treatment for your condition and regular check-ups will help to keep your risk as low as possible.
Stopping Smoking

Smoking causes your arteries to fur up (atherosclerosis) and makes your blood more likely to clot. If you smoke, you are twice as likely to have a stroke, and this risk will increase the more you smoke. Stopping smoking will reduce your risk of a stroke (and other health conditions) – no matter how old you are or how long you have smoked. Giving up is not easy, but it is worth the effort to improve your health.

One of the best ways of avoiding a stroke is not to smoke.

Drinking Sensibly

Drinking too much alcohol raises your blood pressure. The alcohol limit for men in the UK has been lowered to be the same as for women. The Government guideline for both men and women is that:

• you are safest not to drink regularly more than 14 units per week.
• if you do drink as much as 14 units per week, it is best to spread this evenly across the week.

Avoid one-off drinking

When it comes to single drinking occasions, you can keep the short-term health risks at a low level by sticking to a few simple rules:

• limiting the total amount of alcohol you drink on any occasion
• drinking more slowly, drinking with food, and alternating with water.

Drugs

Some types of drugs can increase your risk of stroke by damaging your blood vessels and raising your blood pressure. They include stimulant drugs like cocaine and amphetamines, and drugs that improve sports performance.

Eating healthily

Eating well is essential for a healthy bloodstream.

A good balanced diet can help prevent stroke, heart disease and type 2 diabetes.

The main food groups

Choose a variety from the main food groups.

• Fruit and vegetables
• Starchy foods like bread, rice, pasta and potatoes
• Meat, fish, eggs and other protein
• Dairy food such as milk, cheese and yoghurt
• Fats and sugars (but don't have too much of these)

**Eating well**

Snack on fruit and vegetables Try not to fill up on junk food. Choose healthier options like fresh fruit, vegetables and dried fruit.

Aim to have at least five portions of fruit and vegetables each day. A portion is about 80 grams (three ounces) – for example, an apple or orange, a glass of fruit juice, a large carrot, two broccoli florets, a handful of grapes or three tablespoons of peas.

**Choose low-fat proteins**

Cut down on red meat – choose fish, poultry (with the skin removed), game or vegetarian options instead. Most red meat is high in saturated fat, which can raise your cholesterol levels and clog up your arteries.

**Eat plenty of fibre**

Foods that are high in fibre help to reduce the amount of cholesterol in your blood. Try wholegrain cereals, porridge, brown rice, wholewheat bread and pasta, or grains such as couscous.

**Cut down on salt**

Salt raises blood pressure. Avoid processed food and fast food, which contain a lot of salt. Eat fresh foods whenever you can and, instead of adding salt to your food, try flavouring it with herbs and spices.

**Cut down on fat**

If you have too much fat in your diet, it can clog up your arteries and lead to weight problems. You need some fat in your diet, but try to limit the amount you use and stick to vegetable or olive-based margarines and vegetable or nut oils.

**Watch your weight**

Being overweight puts you at risk of high blood pressure, heart disease and type 2 diabetes, all of which increase your risk of a stroke. To find out if you are a healthy weight for your height, visit your doctor. A healthy diet and regular exercise will help you to lose or control your weight.

**Keeping active**

Just 30 minutes of regular exercise five days a week can halve your risk of having a stroke. You don’t have to do it all in one go – it is just as effective to exercise a few times a day in 10- or 15-minute sessions.
Regular physical activity helps to lower your blood pressure and reduce your risk of having a stroke, type 2 diabetes and heart disease.

Here are some tips to get you started.

• Pick an activity you enjoy. This could be swimming, dancing or T'ai Chi – it doesn’t matter what you do as long as it makes you feel warm and slightly out of breath.

• Don’t overdo it – build up gradually to 30 minutes a day.

• Warm up before exercising and cool down afterwards.

• Find someone to exercise with.

• Be more active during the day – take the stairs instead of the lift or escalator and walk to the shops instead of driving.

If you haven’t been active for some time, especially if you’re over 40 or have a medical condition, get your doctor’s advice before you start. If you feel dizzy, have pain (especially in your chest) or you find it difficult to breathe, stop exercising straightaway and tell your doctor.

Other factors

Stress and depression

Many things in life – like work issues, redundancy, family problems and bereavement – can lead to stress and depression. These not only take a physical toll on your body, but if they are not treated, they can lead to long-term health problems. It is important that you get any help you need from your doctor and other healthcare professionals.

Risk factors for women

There are some things that can increase the risk of stroke for women. High levels of the female hormone oestrogen can make your blood more likely to clot. During pregnancy oestrogen levels rise naturally, but there are also hormone treatments that will cause it to rise, such as contraceptives which contain oestrogen, and hormone replacement therapy (HRT). Always discuss contraception and hormone treatments with your doctor and make a decision that is right for you.

Non-modifiable

You may have an increased risk of a stroke because of things you can’t change. These include the following.

• Family history – you are more at risk if someone in your family has had a stroke.

• Age – arteries harden and become furred up with age, which means older people are more likely to have a stroke.
• Gender (sex) – in people under the age of 75, men have more strokes than women.

• Ethnic background – if you are of South Asian or African-Caribbean origin, you are more at risk.

If you have any of the above risk factors, improving your lifestyle is even more important to reduce your risk of having a stroke.

Although your risk of having a stroke is higher if you have already had a stroke or a TIA (mini-stroke), there are positive steps you can take to reduce your risk. It is important that you:

• take any medication your doctor prescribes

• have regular health check-ups to make sure it is working for you, and

• take your doctor’s advice about your lifestyle.

You may also have had an operation after your stroke to lower your risk of having another one, for example on the arteries in your neck, or within your brain after some types of bleed. Make sure you follow your after-care advice. It’s never too late to change your lifestyle and improve your health.
The Stroke Pathway

The description, validation and acceptance of what is the optimal stroke service is a vast topic and one worthy of a whole project on its own. A sense of the scope of work in this area can be seen at this archive

http://www.strokecenter.org/professionals/resources/guidelines-consensus-statements/

As of late 2016, there is no widely accepted set of guidelines for stroke management. This is arguably for good reason due to the very variable cultural, socio-economic and epidemiological patterns seen across countries as evidenced by the influential series of Global Burden of Disease reports in recent years. For this reason, the World Stroke Organisation has in recent years started to frame what good stroke services should look like. In Lindsey the WSO distinguishes between minimal, essential and advanced stroke services

![Table 1. Health service capacity for stroke care checklists](image)

*These checklists should be used for self-assessment and for stroke services planning. The goal is to achieve as many checkmarks as possible and continually strive to provide the highest level of stroke services that is realistically and reasonably attainable, given local and regional resources and circumstances. CT: computed tomography; ECG: electrocardiogram; ICP: intracranial pressure.

![Figure 2. WSO8 Stratification of levels of stroke service provision](image)

The whole set of advanced stroke services are well captured in this diagram from the same report

![Figure 3. WSO8 Idealised post-stroke service](image)
WSO Guidelines

The same WSO action plan details the key set of evidence based recommendations that the WSO makes for the whole stroke pathway. Shown below in Table 1 are those that apply post-acute stroke care i.e. rehabilitation, secondary prevention and long-term recovery. Note that these are ambitions and not a description of reality.

Table 1 Global Stroke Guidelines and Quality Action Plan Core stroke care recommendations

**Stroke rehabilitation**
1. All patients with acute stroke should have an initial functional assessment to determine rehabilitation needs and receive an individualized rehabilitation plan.
2. All patients who are admitted to inpatient rehabilitation following stroke should be treated on a specialized stroke rehabilitation unit.
3. Therapy should include repetitive and intense use of tasks that challenge the patient to acquire the necessary skills needed to perform functional tasks and activities.
4. Patients should receive adaptive training (such as the use of specialized devices) to improve performance of specific functional tasks.
5. Spasticity and contractures can be prevented or treated by anti-spastic pattern positioning, range-of-motion exercises, and/or stretching. Routine use of splints is not recommended.
6. Healthcare workers and families should be taught to protect and support the paretic arm during movement, and to protect arm during wheelchair use by using a hemi-tray or arm trough.
7. Patients should be made aware of their increased risk for falls and given a list of precautions to reduce their risk of falling.
8. Patients should be assessed for post-stroke pain, including persistent central pain and shoulder pain on affected side.
9. Patients should be assessed for communication deficits.
10. Interventions to improve functional communication for patients with aphasia should be implemented (such as teaching families about the need for ongoing conversation, use of nonverbal strategies).
11. Patients with aphasia should be referred to a speech-language pathologist for individualized therapy to improve communication ability.

**Secondary stroke prevention**
1a. Assess stroke and TIA patients for vascular disease risk factors and lifestyle management issues: smoking, exercise levels, diet, weight, and alcohol and sodium intake.
1b. Assess stroke and TIA patients for vascular disease risk factors: hypertension, diabetes, atrial fibrillation, and hypercholesteremia
1c. Assess stroke and TIA patients for vascular disease risk factors: carotid disease, cardiac disease.
2. Provide information and counselling about possible strategies to modify lifestyle for vascular risk reduction (smoking, weight, diet, sodium intake, exercise, stress, alcohol intake).
3. Referrals should be made to appropriate specialists to provide more comprehensive assessments and structured programs to manage specific vascular risk factors.
4. All patients with ischemic stroke or TIA should be prescribed antiplatelet therapy for secondary prevention of recurrent stroke unless there is an indication for anticoagulation (once a CT has established a diagnosis of ischemic etiology).

5. All patients with stroke or TIA should have their blood pressure monitored regularly. Antihypertensive medication should be initiated before hospital discharge for all stroke patients to treat to individualized targets.

6. A statin drug should be prescribed as secondary prevention to most patients who have had an ischemic stroke or TIA.

7. Glycemic levels should be monitored in diabetic patients with stroke or TIA.

8. Diabetic patients with stroke or TIA should be treated to achieve individual glycemic targets. In most cases, patients should be treated to achieve a glycated haemoglobin A1C level ≤7·0%.

9. Patients with atrial fibrillation or atrial flutter (paroxysmal, persistent or permanent) should receive an oral anticoagulant.

10. Patients with TIA or non-disabling stroke and ipsilateral 50 to 99% internal carotid artery stenosis should be evaluated by an individual with stroke expertise.

11. Selected patients with ipsilateral 50 to 99% internal carotid artery stenosis should be offered and referred for carotid revascularization as soon as possible, with the goal of operating within 7 to 14 days.

**Longer-term stroke recovery**

1. All patients with stroke should be screened for depressive symptoms (ideally using a validated tool).

2. Patients diagnosed with a depressive disorder following formal assessment should be considered for therapeutic interventions – medication, counselling, or combination.

3. Stroke patients should be screened for changes in cognitive status.

3. b Patients with cognitive dysfunction should receive cognitive rehabilitation individualized to their deficits.

4. Patients surviving a stroke, as well as their families and informal caregivers, should be approached by the stroke healthcare team to participate in advance care planning.

5. Patients, families, and informal caregivers should be provided with information, education, training, emotional support, and community services specific to the transition they are undergoing.

6. Patients, families, and informal caregivers should participate in goal setting.

7. People with stroke living in the community should have regular and ongoing monitoring and follow-up with healthcare providers to assess recovery, prevent deterioration, maximize functional and psychosocial outcomes, and improve quality of life.

8. Post-acute stroke patients who experience a change/decline in functional status should be re-assessed, even if months after stroke.

9. Stroke patients should be routinely monitored for post-stroke fatigue during healthcare visits (e.g. primary care, home care, and outpatient) following return to the community and at transition points.

10. Patients, who experience post-stroke fatigue, their families, and informal caregivers, should be taught energy conservation strategies and fatigue management.

(CT, computed tomography; EMS, emergency medical services; MRI, magnetic resonance imaging.)

What may be more useful for the STARR consortium therefore is that this next section of the deliverable focuses on a set of services that are actually implemented and are typical of a high-income westernised service (in this case the UK) that in many ways acts as a model for other regions. That is not to say the UK is
perfect in this sense, far from it. Like all countries it does some things well and some things not so well. There is no country that currently provides a high standard of stroke support across the whole pathway. As Lindsey goes on to state; “The last two decades have seen a major transformation in the stroke field with the emergence of evidence-based approaches to stroke prevention, acute stroke management, and stroke recovery. The current challenge lies in implementing these interventions, particularly in regions with high incidences of stroke and limited healthcare resources.”

**Typical NHS stroke pathway in the UK**

The National Stroke Strategy provides the foundation for defining stroke services and outlines what is needed to create effective stroke services in England. The strategy identifies major stages in the stroke patient pathway and stresses a need to reorganise the way in which stroke services are delivered, from prevention through to support for those who have experienced a stroke.

A whole pathway approach to the provision of stroke services is crucial to maximising the clinical outcomes for patients, the resultant quality of life and their experience of stroke services. The first 72 hours of care is vital to ensure the optimum clinical outcomes for stroke survivors. This needs to be underpinned by an effective whole system pathway for assessment, discharge and repatriation to local stroke services, subsequent rehabilitation and longer term support. A critical aim is that such a pathway will reduce stroke mortality, reduce the level of disability following a stroke, and reduce the length of stay of stroke patients in bed-based services. Placing patients on the correct pathway (TIA, acute or hyperacute) will maximise the likelihood of best possible outcome and allow the NHS to best use its resources in a local area.

The NHS specifies the pathway phases in terms of a sequence of services as shown here;

![Pathway Phases](image)

Part C, the Acute phase, is further sub-divided into

- Hyper acute stroke care
- Acute stroke care (including in-hospital rehabilitation services)
- Transient Ischaemic Attack (TIA) services
- Tertiary care services (e.g. neuro and vascular surgery referrals)

Part D, Community rehabilitation, is split into Early Supported Discharge (ESD) and Stroke Specialist community rehabilitation. The global flow is captured in Fig.4 overleaf.
For reasons of space we will only describe best practise in parts of the service that are most applicable to STARR users i.e. likely to be from near the start of early supported discharge (with secondary prevention efforts running in parallel) through to longer term care. These service specifications are based upon the following comprehensive and current evidence base and agreed best practice, referenced internally at the Stroke Association (UK);


*Stroke Service Standards* (2010) British Association of Stroke Physicians


*Supporting Life after stroke* (2011) Care Quality Commission
Early Supported Discharge (ESD)

ESD allows patients to leave hospital ‘early’ through the provision of intense rehabilitation in the community at a similar level of care to that provided in the hospital. An ESD multi-disciplinary team of nurse, therapists, doctors and social care staff work with the patient and family for up to 6 weeks to help increase independence and quality of life.

An ESD team should be stroke specific and able to commence support within 24 hours of discharge. Survivors should get active therapy of 45 minutes per discipline up to 5 days per week. A single point of contact should be available between the patient/carer and ESD staff. ESD staff should train carers to recognise common causes of illness that can result in avoidable readmissions, such as constipation or urinary tract infection.

An ESD team should comprise of many or all of the following roles: Occupational therapist, Physiotherapist, Speech and Language Therapist, Stroke physician, Nurse, Social worker, Rehabilitation assistant, Clinical Psychologist, Dietician orthotic technician, Orthoptic technician. Some or all of these clinicians may thus be an ongoing factor in the life of a STARR system user.

Stroke Specialist Community Rehabilitation

This is a range of services that are in place and easily accessible to support the individual long-term needs of individuals, their carer/s and families, encouraging self-management where appropriate. Comprehensive social care should be provided to all patients and their carers that need it. The desired aspects of best practise are that:

- A single point of contact is provided when patients leave hospital.
- All stroke survivors discharged from hospital who have residual stroke-related problems are followed up within 72 hours by specialist stroke rehabilitation services for assessment and ongoing management.
- Any stroke survivors referred to a social worker will receive an assessment within 72 hours of receipt of the referral.
- Goals incorporated into a personalised care plan that allows the patient to take ownership of their rehabilitation and reviewed regularly (every 4-6 weeks) with the patient throughout the treatment period.
- Active therapy at a level appropriate for obtaining rehabilitation goals for as long as they are continuing to benefit from the therapy and are able to tolerate it (target for 45 mins per discipline, 5 days a week).
- The GP and other relevant community services are informed that a stroke survivor has been discharged home or to another hospital prior to discharge.
• Age appropriate provision made for the social care requirements of stroke survivor prior to discharge, e.g. domestic tasks (such as shopping and laundry)

• Adult social services provide advice on aids and adaptations to daily living

• Review of home environment, usually by a home visit by an occupational therapist, to adapt to patient needs where patient remains dependent in some activities

• A carers assessment should be completed for each carer with links to carer support groups made and family support organisations and followed up

Specialist stroke rehabilitation, support and any appropriate management plans will address the following issues either directly or by seamless onward referral where required:

• Mobility and movement (including exercise programmes, gait retraining, mobility aids and orthotics)
• Upper limb rehabilitation
• Management of spasticity and tone
• Sensory impairment screening and sensory discrimination training
• Falls prevention (including assessment of bone health, progressive balance training and aids)
• Cognitive rehabilitation (including addressing impairment in attention, memory, spatial awareness, perception, praxis and executive function)
• Communication (including aphasia support twice weekly during the first 20 weeks, techniques or aids for dysarthria and apraxia, information about local groups)
• Everyday activities including provision of daily living aids and equipment (e.g. dressing, washing, meal preparation)
• Emotional and psychosocial issues (e.g. depression, adjustment difficulties, changes in self-esteem or efficacy, emotionalism)
• Swallowing (including swallowing rehab, maintenance of oral and dental hygiene, nasogastric tube feeding, gastrostomy)
• Skin integrity (i.e. pressure care and positioning)
• Nutrition (including specialist nutritional assessment, nutritional support)
• Visual disturbance
• Continence (bladder and bowel)
• Social interaction, relationships and sexual functioning (including psychosocial management or medications)
• Pain (assessed regularly using validated score, referred to specialist where indicated)
• Home assessment (including need for larger scale equipment or adaptation)
• Return to work (including referral to specialist in employment or vocational rehabilitation)
• Driving
• Financial management and accessing benefits
• Community leisure and exercise classes are available and promoted to stroke survivors, who are then supported to attend
Stroke survivors are aware of and offered options to promote wellbeing, including peer-led support groups, engagement in community activities and professional psychological therapies including community mental health services.

Telephone counselling support available for three months

Long term care
Stroke survivors and their carers should be enabled to live a full life in the community over the medium and long term (>3 months). Support is required from local services to ensure appropriate, tailored support is provided to assist re-integration into the community and maximise the quality of life experienced by stroke survivors, their carer/s and families.

The desired aspects of best practise are that;

- Ongoing physical, speech and language, continence and other required therapies are provided where clinically appropriate to meet patient needs
- Carers of stroke survivors with stroke are provided with a named point of contact for stroke information, written information about the stroke survivors diagnosis and personal care plan, and sufficient practical training to enable them to provide care
- Carers are provided with clear guidance on how to find help if problems develop
- The patient and family will be aware of their single named point of contact
- All stroke survivors receive a review and onward referral to appropriate multidisciplinary team (MDT) members at six weeks, six months, 12 months and then annually that facilitates a clear pathway back to further specialist review, risk factor screening, advice, information, support and rehabilitation where required.
- Information from reviews should be shared across the entire team involved in delivering care to the stroke survivor, including with the stroke survivor themselves and their GP.
- Stroke survivors and their carers are enabled to participate in paid, supported and voluntary employment

Secondary Prevention
Obviously of major relevance to STARR, the NHS specification on secondary prevention concentrates on assessing individuals for their risk factors and giving them information about possible strategies to modify their lifestyle that can reduce their risk. It urges that GPs need to actively manage these conditions in line with national guidelines. The desired aspects of best practise are that;
All stroke survivors will have their risk factors assessed as soon as possible and certainly within one week. A personal care plan for secondary prevention as part of the stroke team’s assessment is passed onto primary care.

Stroke survivors are monitored regularly in primary care on a yearly basis at minimum.

Hypertension is managed so systolic blood pressure is below 130 mmHg; treatment should be initiated prior to discharge or at two weeks.

Anticoagulation (e.g. Warfarin) for individuals with atrial fibrillation and where not contraindicated; prescribed before discharge or plans to anti-coagulate as out-patient whichever aligns with guidelines to administer 2 weeks following stroke onset.

All patients with ischaemic stroke, not in atrial fibrillation, to have anti-platelets medication unless contraindicated.

All patients who have had an ischaemic stroke or TIA should be offered a statin drug unless contraindicated.

Smoking cessation, alcohol, tailored exercise programmes and healthy lifestyle advice for all stroke/TIA survivors.

Participating GPs produce and maintain a register of patients who have had a stroke or TIA, forming a suite of indicators to provide quality of care.

Measures for secondary prevention introduced as soon as the diagnosis is confirmed, including discussion of individual risk factors.

Information and advice strategies to ensure that clear, consistent, culturally sensitive messages are being given to those who have had a stroke, their families and those at high risk.

Many of these ambitions will be obvious and current in the mind of stroke survivors and their carers who may encounter a STARR system. Therefore, STARR designers should be aware of these supplementary actors and intentions as they influence the life of a service user.

Regardless of the good intentions above to implement such a service, in most EU countries the reality of the service can be summarised as follows. If the patient has achieved a certain level of independence, they are discharged home where rehabilitation is continued in the community setting. Otherwise, and more commonly throughout the EU, patients are transferred from the acute stroke unit to a rehabilitation centre for further care. The period of inpatient rehabilitation varies considerably across Europe, from weeks to several months. After this inpatient rehabilitation phase, patients are discharged to either nursing home care (very dependent and/or weak patients) or back into the community (home). Patients in nursing care homes will be cared for but have very little further rehabilitation potential.

Patients discharged home are confronted with an exit from the rehabilitation centre and variously prepared for this transfer. Across Europe, the delivery of further rehabilitation once discharged into the community is highly variable; mostly nothing, sometimes one hour of therapy per week for a limited period of time. Nevertheless, these patients may have considerable further rehabilitation potential that is left unused, and it is not unusual for them to feel abandoned by the stroke care system.
Telerehabilitation

The remote support of healthcare interventions has a long, well-intended history of promising more than it has so far delivered. In many respects this is because the intention was running well ahead of time of the actual physical ability to deliver remote care. This, as has been seen in many EU funded projects, was due to limitations in device design (remote client and sensor), the necessary communication bandwidth, and the financial willingness to invest in such platforms. These barriers are now finally being overcome in what is now an extremely topical and competitive marketplace and research arena. As Dorsey\textsuperscript{11} recently stated;

“.. three trends, all linked, are currently shaping telehealth. The first is the transformation of the application of telehealth from increasing access to health care to providing convenience and eventually reducing cost. The second is the expansion of telehealth from addressing acute conditions to also addressing episodic and chronic conditions. The third is the migration of telehealth from hospitals and satellite clinics to the home and mobile devices. “

These positive developments are not to say that the matter is settled; far from it. Telehealth still suffers from having a weak evidence base and to counter this clinical groups are developing research agendas to put it on a stronger footing. Dinesen et al.\textsuperscript{12} have succinctly profiled the research landscape and have outlined the following questions yet still to be fully addressed by telehealth researchers.
This is clearly a very wide reaching set of themes cutting across many clinical, social and technological topics. Although this project pre-dates this table, many of these are relevant to STARR and will be touched on during the project lifetime.

To give some focus to this report we now turn mainly to issues directly relevant to stroke whilst acknowledging that the wider context is as follows; telehealth -> telerehabilitation -> telestroke i.e. with each successive category being a subset of the previous one.

So, what is the need for telerehabilitation in stroke? Given the service specifications (intended and actual) outline above, what is the role for remote monitoring and why?

Firstly we should note that one of the earliest applications for telehealth was in fact in acute stroke13.

Table 2. Focus areas for personalized telehealth research. (source Dinesen12)

<table>
<thead>
<tr>
<th>Focus areas for personalized telehealth research. (source Dinesen12)</th>
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</thead>
<tbody>
<tr>
<td>1. Patient</td>
</tr>
<tr>
<td>• Assessment of personal engagement in own health through the use of telehealth technologies (screening and monitoring)</td>
</tr>
<tr>
<td>• Self-determination and motivation with regard to the use of new telehealth technologies</td>
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<tr>
<td>• Health literacy, eHealth literacy, technology literacy, contributions to design features of technology and interaction with telehealth technologies</td>
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<tr>
<td>• Patient or patient involvement</td>
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<tr>
<td>2. Home</td>
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<tr>
<td>• Integration of smart home telehealth technologies (widespread and health devices and software, Internet of Things)</td>
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<tr>
<td>3. Health care professional</td>
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<tr>
<td>• Communications for and between providers and patients (telehealth through mobile, wearable, and remote monitoring)</td>
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<tr>
<td>• Telehealth training and education, including designing combination of knowledge and practice</td>
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<tr>
<td>4. Health system design, organization, and practice</td>
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<tr>
<td>• Cross-sector interoperability using telehealth technologies (Accessible Care Organizations, integrated care, medical homes)</td>
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<tr>
<td>• Telehealth in models of chronic illness management</td>
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<tr>
<td>• Adoption of telehealth programs in clinical practice</td>
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<tr>
<td>5. Business</td>
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<tr>
<td>• Use of telehealth technologies</td>
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<tr>
<td>• Design of unobtrusively technologies</td>
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<tr>
<td>• Development of sensor technologies for detection of fluid in the body, sleep patterns, etc.</td>
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<tr>
<td>6. Data systems and infrastructure</td>
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<tr>
<td>• Integration of telehealth devices with electronic health records and cloud databases</td>
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<tr>
<td>• Integration of personal health records data and telehealth devices and systems</td>
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<tr>
<td>7. Data analytics</td>
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<tr>
<td>• Algorithms for unobtrusive data collection, disease, and outcomes</td>
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<tr>
<td>• Innovative data analytic approaches for integrating data from various sources, including predictive, personalized, and contextual analytics</td>
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<tr>
<td>8. Development of new telehealth technologies</td>
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<tr>
<td>• Accessing mobile, intelligent, and multidimensional telehealth technologies</td>
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<tr>
<td>• Enhancing the matching of patient preferences and telehealth use</td>
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<tr>
<td>• Anticipating telehealth interventions still to be assessed</td>
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<tr>
<td>9. Implementation telehealth technology standards</td>
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<tr>
<td>10. Research method</td>
</tr>
<tr>
<td>• Multidisciplinary assessment of the effectiveness of new telehealth solutions</td>
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<tr>
<td>• Advances in tracking, data transmission, and exchange of telehealth data (multimedia analytics vs. data and forward)</td>
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<tr>
<td>• Rapid cycle design evaluation vs. traditional randomized controlled trials</td>
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<tr>
<td>11. Privacy and security policy</td>
</tr>
<tr>
<td>• Addressing different cultures of privacy (political issues) for patients</td>
</tr>
<tr>
<td>• Enhancing data security (new advances in privacy, wearable, and cloud-based systems configurations)</td>
</tr>
</tbody>
</table>

- Legal, regional, and international regulatory requirements (privacy guidelines, consent) |
- Policy policy |
- Telehealth across state and international boundaries |
- Professional licensing and standards |
- Variations in interprofessional and international telehealth policies and financing

| Page | 20 | D2.1. Self-management in Stroke |
This 1999 study was an attempt to provide remote neurologist support for the uptake of time-sensitive administration of thrombolytic drugs. This paradigm has now been so successful in the USA that the largest care provider for patients with stroke in the country is now not a major medical centre but a telemedicine company.\(^\text{14}\)

But the story is different for rehabilitation. That current, therapist-present, stroke rehabilitation enhances stroke recovery is evidenced by several meta-analyses.\(^\text{15}\) Indeed, strong evidence of benefit and knowledge of prognostic indicators of recovery has been used to produce an algorithm designed to aid clinical decisions about which physical therapies to provide for individuals.\(^\text{17}\) However, financial pressures mean that evidenced-based stroke rehabilitation cannot usually be provided as needed. For example, stroke survivors receive approximately 24 minutes of exercise therapy each working day in the Netherlands\(^\text{18}\) and 12 minutes in the UK\(^\text{19}\) when at least 45 minutes is recommended in clinical Guidelines.\(^\text{20}\) Evidenced-based stroke rehabilitation is not being delivered to the people who need it and so innovation is required for rehabilitation delivery to people in their homes. Early supported discharge services (ESD) are often provided but therapist time is wasted travelling between stroke survivors’ homes (Randall, personal experience). Therefore, the evidence that ESD is cost effective if adequate support is delivered\(^\text{21}\) is not adhered to in the real world.

When it is possible to link people around the globe using existing ICT the obvious solution is to connect home-based stroke survivors with hospital-based therapists. Increased telerehabilitation in stroke offers the step-change required to ensure that stroke survivors receive the evidence-based rehabilitation they need and to fill the gap between WSO intentions and real-world provision.

As mentioned above, telerehabilitation is not a new idea. A systematic review\(^\text{22}\) suggests that therapist-present and telerehabilitation could produce comparable outcomes. But, telesstroke rehabilitation research to date has mostly been: small scale; focused on discrete interventions e.g. finger and wrist movement practice; and based on telephone contacts with some specialised single items of ICT e.g. a desktop videophone.\(^\text{22}\) In clinical practice, therapists are experimenting with exercise apps and other technology but telerehabilitation has not penetrated far. It is still rare to encounter telerehabilitation for stroke survivors.

An exception is an initiative providing a telerestroke service for people living in the Western Isles of Scotland and admitted to the hospital on Stornoway http://sctt.org.uk/programmes/health/stroke/telestroke-rehabilitation/. This telerestroke service consists of specialist clinical leadership from a consultant physician on the mainland via a video conferencing unit. Such services do not connect stroke survivors in their homes with evidenced-based interventions, focusing on rehabilitation, directed by specialist therapists.
## Self-Management (SM)

Self-management (SM) can be defined as having the knowledge, skills and confidence to control life after stroke. Self-management has received growing attention as an effective and cost-effective approach for long-term condition management. It is closely related to efforts to prevent readmission found in the telehealth sector. Why it is needed, from the personal perspective of the patient, is well-captured in this graphic by information designer Anna Vital.

![WHY PEOPLE GIVE UP](image)

As is well accepted, growing pressure on non-acute services due to a larger aging population, more of whom survive stroke, means that according to the Health Foundation, a leading health strategy charity in the UK; "The number of people with multiple long-term conditions is predicted to rise by a third over the next ten years. Almost one in three of the population in the UK live with one or more long term conditions. Self-management support has been emphasised as a top priority for health and social care in most developed countries."

(Source: Health Foundation: Implementing Shared Decision Making in the UK)

So, what is SM in practise? Critically, it involves paying more than lip service to the idea of patient involvement. At its core is the notion that the patient is the ultimate authority on their condition and they must be consulted and treated as an equal partner during the treatment period. SM does not necessarily mean going it alone. Typically, it means providing encouragement and support to a stroke survivor and their family/carers to allow them to take the main role in dealing with their chronic condition by making informed decisions about healthcare and by engaging in more healthy behaviours.

SM therefore involves a sharing of expertise between clinician and patient. Both parties must be committed to the process and clinicians must recognise that patients can be competent decision makers about their own lifestyle and condition. Fig. 5 below shows the wider concept;
However little is known about which outcomes of supported self-management are valued by patients, their families, health professionals and those who commission self-management services. In other words, what do patients expect to get out of self-management if they engage with it? The review by Boger\(^25\) found six relevant measures in the literature. They are applicable knowledge, independence, a positive network, being ‘themselves’, self-management skills and attributes and optimal psychological and social health. These do indeed seem applicable to sub-acute and chronic stroke.

In a purely academic sense, there is evidence that exists for the effectiveness of self-management. The paper by Lennon\(^26\) found that evidence is limited in comparison with physical rehabilitation as only 15 studies were available for the review. However, significant treatment effects were found, with statistically significant results reported in favour of the self-management group.

More specifically, significant treatment effects in favour of the self-management intervention were found in 6/9 randomised control trials and in 3/6 non-randomised trials. Four of the trials had subject groups numbering more than 100. Outcomes included measures of disability, confidence in recovery, stroke specific quality of life, short-form SF-36 score and general quality of life measures such as self-efficacy and mood assessment. This wide range of outcome measures used prevented comparison across studies.

**Peer-to-peer support networks**

Connected communities for health are growing in their membership and their diversity. Several platforms bring together people with interests in health and care within countries and across the world to support each other, share learning and provide platforms for tracking their health data or helping them manage their condition. MedHelp\(^27\), PatientsLikeMe\(^28\) and HealthUnlocked\(^29\) are just three of these social networks for health. The only such platform that is stroke specific is My Stroke Guide\(^30\) developed by the Stroke Association in the UK. Our plan in STARR is to integrate some of the help functionality from My Stroke Guide into the STARR platform in the native language of our end users.
Generic Requirements
This short section suggests a set of top-level generic requirements for STARR. The intention is to add to the more complete sets of requirements that are given in other workpackages after formal interaction with workshops and focus groups. These current requirements and levels of priority come only from domain experts at the Stroke Association in the UK.

Functional
Blood pressure measurement. Priority = high.
Weight measurement. Priority = high.
Level of physical activity recording. Priority = high.
Diabetes status monitoring. Priority = high.
Inclusion for hemi-paresis. Priority = high.
Configurable to the user (interface). Priority = medium.
Configurable to the user (functionality). Priority = medium.
Inclusive for patients with visual neglect. Priority = medium.
Inclusive for patients with aphasia. Priority = medium.
Data recording – it should always be clear when the system is recording data, and whose data it is. Priority = high.

Non-Functional
Reliability – system should be long lasting. Priority = high.
Reliability – system should be accurate. Priority = high.
Reliability – system should report low or failing power. Priority = medium.
Usability – system should be intuitive and acceptable by the target user groups. Priority = high.
Undue alarm - the system should not cause unnecessary anxiety in a user due to a single reading. Priority = high.
Stigma – the system should not reinforce, especially in public, the stroke status of the user and thus cause social stigma. Priority = medium.
Conclusion

This intention of this deliverable was to paint a picture of some of the major factors in the life of a stroke survivor, factors that those not accustomed to working in healthcare are unlikely to be aware of. This is important for the STARR consortium within this first year as many design decisions may make assumptions about the user and they context in which they encounter STARR. Seventy percent of the STARR consortium do not work directly with stroke survivors. So, this deliverable is needed specifically to point out which actors will be in the life of a stroke survivor and which processes the survivor and carer are likely to be going through. These factors will impact on the engagement of users with our system.

To that end, we have described in lay language what the common risk factors are for primary and subsequent stroke and have done so in a way that the text can be directly used within aspects of the STARR platform. The report describes in detail the healthcare treatment schedule, the ‘pathway’ for stroke both as idealised by the World Stroke Organisation and as instantiated in practise by the National Health Service in the UK. Next, we reviewed the evidence for telerehabilitation and especially that for stroke and point out the reasons for low take up of such mechanisms so far. But it is worth repeating that the prospects for telestroke are rapidly improving due to economic pressures on acute and intermediate health services and due to advances in technological feasibility (bandwidth, device reliability etc.). Next, we explored the central notion of self-management in stroke, an idea well described in the literature but only marginally implemented in practise thus far. Finally, we suggested some brief high-level requirements that a self-management support platform should be aware of.

With all that said, it is vital to reiterate what it is about stroke that may prevent lifestyle modification and any reduction in risk of subsequent cerebrovascular events. Stroke is firstly a shock, both to the recipient and their support network. It usually happens without warning and the impairment is severe and sudden. A survivor will be traumatised and have little prior knowledge of stroke or its consequences. Very often, a profound fatigue sets in which can precipitate depression and a downward spiral moving from good intention -> easy fatigue -> rehabilitation plateau -> subsequent increased health risk. Added to this is that almost all stroke survivors will have other co-morbidities to contend with and issues around adherence to medication and risk are very real.

It is only by being aware of the issues in the previous paragraph and the wider themes described in this deliverable that designers of systems such as STARR can hope to achieve success.
References


27. www.medhelp.org

28. www.PatientsLikeMe.com

29. https://healthunlocked.com