Stroke

Overview
Stroke is a complicated, heterogeneous condition with acute onset but complex and enduring treatment and follow-up. Consequently, stroke care is complex and covers a whole spectrum of care including acute care, rehabilitation and long-term care with in-hospital, outpatient and community-based care. Stroke care is thus per definition multidisciplinary and the integration of care is of particular concern.

Care Delivery Shortcomings

Prevention through supported self-care
Existing tools are too simple, not personalised and lack integration:
Current approaches to nutrition and supplementation are often based on single advice without lasting support. Current tools mainly focus on diet, take a quite simple approach, do not sufficiently personalise according to patient characteristics and lack the support required to be successfully adopted by the majority of those at risk / patients. Available approaches seem not to have considered that some goals are easier to achieve than others and that some goals need to be prioritised over others. Such nutritional support is mainly stand-alone and not yet, as it should be, well integrated with day-to-day activities. Many studies also only report results for all strokes combined and there are limited data on diet in relation to different types of a stroke. Where physical activity is addressed, this is mainly in isolation from diet. Most activity trackers also lack the accuracy necessary for medical decision making and lack integration functionalities towards EHRs or medical records.

Socio-economic disparities exist:
Across Europe primary and secondary prevention strategies are not working well enough to control hypertension that is one of the main controllable risk factors for a stroke. Existing racial disparities in stroke incidence highlight the importance of stroke prevention interventions aimed at minority groups. Current efforts to reach patients with risk factors for stroke depend on public awareness campaigns and the action of GPs. In some countries like Sweden, pharmacies offer for example “drop-in” hypertension measurements. In the first case, effects will only result if patients themselves are able to recognise whether they may be at risk. In the case of GP and/or pharmacy interaction, a GP can use specific knowledge of hypertension risk factors to advice - and warn - a patient.

Lack of bi-directional connectivity of devices:
Connectivity is another issue with most products on the market. If connectivity is available it is unidirectional, only supporting transferring values out of the device. Any input, including adaptation to therapy parameters, therefore needs to be manually set. There are innovative, medical grade devices, but these tend to be costly and therefore only suited to research use rather than widespread adoption.

No real harnessing of ICT and technology features in health promotion:
ICT “tools” today do not take real advantage of ICT but print information (perhaps in PDF) for clinicians and patients. Online tools we have found are limited to a single language domain, and not integrated even with health records.

Puting the scope of responsibility only in individuals to change their behaviour is futile, as social determinants and social aspects affect individual’s capacity to change their behaviour.

Early detection and diagnosis
Risk assessment online tools we have found are limited to a single language domain, and not integrated even with local health records or professional platforms and records. A survey of the state of the art in the market showed the use of pull media only and no interface with health systems either to draw risk parameters or to deliver assessment results back into the relevant systems.

The operation of current risk assessment models is imperfect: The ASCVD risk assessment for example was found to overestimate hypertension risk in adults, both for those without diabetes overall, and across socio-demographic subgroups. Another tool, SCORE, can be used by health professionals to assess their patients, but it is not integrated into their own systems and relies on manual entry of patient parameters by the health professional. Further to this, these tools in most cases “tend to use ‘snap-shot’ measurements of risk factors taken at the time of assessment – such as cholesterol levels and blood pressure – to predict the patient’s overall risk of cardiovascular disease. They do not account for a patient’s medical history and how their risk factors have changed over time, nor do they differentiate the risk by specific heart and circulatory diseases, such as heart attacks, strokes, heart failure or abnormal heart rhythms.” Another shortcoming of such score assessments is that they measure a 5 or 10 year risk for patients and thus under-estimate the life-time risk for younger patients, who are increasingly affected by a stroke.

Lack of personalized treatment incentives: Former epidemiologic studies have identified major overarching causes of stroke such as hypertension, cigarette smoking, diabetes, dyslipidemia, atrial fibrillation and carotid stenosis. While general recommendations can be given to patients to treat these conditions, it is currently unknown how a given patient is individually affected by these risk factors. Importantly, most of the risk factors are currently undertreated in the population. Likely, this can be attributed to the lack of personalized treatment incentives.

Lack of knowledge of stroke triggers: Much is known about long-term stroke risk factors, less however about short-term risk factors, or triggers, for stroke.

Patients are often not reached early enough: Elevated blood pressure (BP, HBP) and some of the other stroke risk factors are often without symptoms. As a consequence, many people suffer from hypertension without being aware of it, and their condition is not treated and thus they are at risk to develop a stroke. To avert the risks of hypertension, it is important to reach those with elevated blood pressure earlier than today, so that treatment is initiated in a timely fashion and the incidence of complications reduced. Treatment of
hypertension, whether through medication or lifestyle changes, remains one of the most effective strategies in reducing stroke risk, but hypertension remains undertreated in the community.

**Acute stroke treatment in hospital and early supported discharge**

*Current treatment paradigms do not consider individual differences:*

This supports the assumption that stroke care could be significantly improved by more personalized risk calculation and individualized therapeutic recommendations. Data sharing and infrastructure needs must be addressed, such as integrating highly heterogeneous multi-scale data sources, integrating omics data into clinical care or integrating imaging data. There also rarely seems to be no real-time tracking of EMS or prior transmission of patient data.

*Treatment of acute ischemic strokes is highly time-dependant:*

Thus, lead-time reduction for treatment is critical. Many patients present too late in the hospital to receive treatment.

*Lack of semantic interoperability is still a significant barrier to re-use of data from diverse sources:*

There is a current lack of implemented standards for clinical and research data. This is ranging from lack of specifications of what data should be collected in what situation to how that data should be technically represented and communicated securely across organizational and national borders.

*Lack of collaboration and supporting tools hinders health and social care professionals from obtaining a holistic view of the patient care process:*

Poor patient participation and insufficient interaction between health and social care providers and patients confirm the need for tools to improve teamwork and to meet patients and informal caregivers’ information and communication needs.

*Deficits in communication and collaboration during the discharge planning process are common:*

One big area of concern to patients and carers is the organisation of discharge from hospital as the move from being cared for in hospital by a team of professionals, to being at home and the responsibility of themselves and their carers.

**Post-stroke rehabilitation**

*Need to personalise rehabilitation:*

After the patient has left the hospital, gaps in care often occur and input in terms of rehabilitation therapy decreases or stops entirely. Since the rehabilitation success can make the difference between the need for 24/7 care or independency, there is dire demand to identify individual factors and therapy options to allow specifically tailored rehabilitation treatment for optimal outcomes after stroke. The success of rehabilitation (beyond restoring basic independence) depends on the ability to adapt the therapy programmes to individual patient needs which in turn depend on a number of factors such as the nature and severity of deficits, patient expectations, and caregiver support.

*Lack of longer-term provision of rehabilitation:*

A recent systematic review revealed that, although generally appreciated, rehabilitation was often perceived as insufficient and prematurely withdrawn and stroke survivors and caregivers felt more
progress could have been achieved with longer therapy. Integrated tools that empower the patients to identify co-morbidities (such as a depression) are missing. Stroke survivors have substantial information needs which changes over time. There is, however, not much done about provision of information needs of stroke survivors to facilitate self-care using ICT-tools in general during rehabilitation, especially home-based rehabilitation from the patient’s perspective.

**Lack of rehabilitation is a big bottleneck in stroke treatment:**
The demand for rehabilitation increases simultaneously to rising number of strokes worldwide. Not enough information about ICT tools is promoted to facilitate the recovery process for stroke survivors.

**Difficulties in managing technology:**
There are studies revealing that people with acquired brain injuries after a stroke could have a variety of difficulties in managing technology, such as problems with handling, recognizing, and finding functions on the mobile phone or computer. Barriers which need to be taken into account by mhealth applications are sensory and motor impairments as well as limited vision and impaired speech.

**Chronic care and monitoring**

**Current devices for collecting information on the health status of the patient lack medical grade quality or innovative integration in effective systems:**
Apps developed without the involvement of clinicians and other necessary experts raise a number of concerns, e.g. about measurement accuracy and appropriateness of content.

Thousands of apps with relevant features are available in the stores, but the vast majority are posted under “fitness” or “wellness” categories and are labelled “not for medical use.” Few can claim endorsement by experts in the field, or even that they provide appropriate data security.

**An adequate approach to systems integration and interoperability is rare in current solutions**
threatening vendor lock-in, even making re-use of collected data impossible. Uncertainty about data quality makes it difficult for healthcare professionals to use, given the liability they are subject to. Devices can be obtrusive if used excessively and stigmatising if they are not well designed. Patients with hypertension desire unobtrusive ways of managing their condition.

**Low-cost long-term monitoring** and re-assurance for patients who may have had the event many years ago. Tools to provide information and avoid stigmatisation as well as social exclusion of prevalent stroke patients.

**Monitoring of health diet and lifestyle**
Very little is known about the dietary habits and nutritional needs of stroke survivors. According to a recent literature review by Serra et al (2017), it appears that a combination of screening methods, including food record, laboratory and malnutrition screening tools assessments may be beneficial to assess the dietary intake adequacy of stroke survivors.
Reintegration

This field is affected – up until now – by a lack of data, and it is no wonder that no guidelines for interventions exist that predict return to work force.

The consequences from having a stroke are different from patient to patient. While some suffer from anxiety and depressions, others become half-paralysed. Hence, guidelines predicting the return to work force remain challenging. It remains unclear, which individual factors determine reintegration.

Integrated Care Procurement Objectives

1. Address lack of electronic care record data integration from technologies designed to motivate and educate people as well as enhance the interface between person and their care team.

**Related Integrated Care keywords:**
- DATA AND INFORMATION SHARING
- SERVICE, FUNCTION AND CARE INTEGRATION / COORDINATION – TRANSITIONS

2. Address lack of integration of nutritional and physical activity information and advice: Innovative solutions will be expected to be supported which allow patients to track a range of parameters including blood pressure, weight, impedance measured fat, fluid intake, muscle action, physical activity, carbohydrate intake and stress levels.

**Related Integrated Care keywords:**
- DIGITAL HEALTH
- HOLISTIC AND COMPREHENSIVE APPROACH
- SELF-CARE AND SELF-MANAGEMENT

3. Link stroke risk assessment results with an interface for care practitioners to ensure that the identified person with high risk of stroke can be monitored and followed up. Risk calculation and therapeutic recommendation tools should be personalised, addressing data sharing and infrastructure needs such as integrating highly heterogeneous multi-scale data sources, integrating omics data into clinical care or integrating imaging data. The provision of multiple channels to establish bi-directional communication of text, images, voices, video should be addressed as well.

**Related Integrated Care keywords:**
- DATA AND INFORMATION SHARING
- DIGITAL HEALTH
- PERSONALISED CARE

4. Improve transition from hospital to community setting- Innovative solutions should tackle the need of patients and family carers receiving the necessary training to enable a successful transition to the home environment. Patients and family carers often receive insufficient advice on the psychological and emotional impact of a stroke and how they can manage these complex feelings. Furthermore, it seems to be difficult to find and access information and assistance on care and support services after discharge from hospital. Solutions should also enable a better addressing of the current lack of proactive follow-up either from primary care, the hospital, allied healthcare professionals, and/ or social care services.
5. Find Anti-Coagulation Dosing Software system, interfacing to relevant (e.g., hospital and GP patient records) IT systems, as well as to device and any mobile applications to support safe transmission of meter results to software.

Related Integrated Care keywords:
- DIGITAL HEALTH

6. Answer client information needs that change over time. ICT tools shall facilitate self-care during rehabilitation especially home-based rehabilitation from the patient’s perspective.

Related Integrated Care keywords:
- DIGITAL HEALTH
- SELF-CARE AND SELF-MANAGEMENT