

## User Perspective and Co-Creation of Health



*The user perspective and approaches across different sectors are paramount for co-creating health.*

**Careum Research picks up on current issues concerning health care in private households. Pivotal is the “co-production” of patients, relatives and health professionals. The aim is to acquire knowledge of innovative care and living arrangements – on an interdisciplinary and cross-sectoral basis.**

### **User-centered approaches to care provision**

In keeping with the motto of “outpatient before inpatient”, new forms of healthcare at home are a considerable need from both a social and healthcare policy perspective. Elderly or chronically ill people should be offered innovative forms of care provision and living arrangements in the place where they actually reside, as well as contact with the relevant service providers. This should tie in with their daily routine. Since providers are organised on a piecemeal basis with little coordination, there is a particular need for integrated provision. Careum contributes by helping to develop research into care provision in Switzerland. Knowledge is gathered, published and put into practice in cooperation with partners on both an interprofessional and intersectoral basis.

### **Care provided by relatives**

A practice-oriented examination looks into the reconciliation of the care of relatives with the other tasks in life. About half of the population is facing the challenge of looking after

relatives in need of care at some point in life. Without relatives, the often time-consuming domestic support and care could not be maintained neither financially nor structurally. Their voluntary work is enormous. To fit «caring» into the rest of people’s entire lives requires new forms of care and co-creation of health which use innovative approaches to ensure the quality of community-based care. The user perspective and approaches across different sectors are paramount.

### **To live self-determined with a chronic illness**

Living with chronic illness and multimorbidity, health literacy, support in self-management and empowerment: these are the formative priorities of Careum Research and particularly of the competence centre for patient education. The Careum Foundation has also been performing important work in the areas of patient involvement and competence since 2009.

Careum Research, as the research institute of the Kalaidos University of Applied Sciences, Department of Health Science, is involved in research focused on practical application. Academic debates on theory are relayed in publications with a practical slant and widely discussed in terms of the overall interests of society. An interdisciplinary research team consisting of researchers from care, health, social and legal sciences works on the main projects, often cooperating with international partners.

### **“Young Carers und Young Adult Carers”**

In Switzerland, many people are still unaware that children, adolescents and young adults look after relatives who require care. Careum Research is looking to close this gap with a research and development programme over a period of years. This involves devising specific measures to support these children and young people.

- *Sub-projects 1 & 2 (Ebnet Foundation): qualitative data collection and development of a practice tool* for health care and social services professionals.
- *Sub-projects 3–5 (Swiss National Science Foundation): quantitative survey and qualitative interviews* with children, adolescents and their relatives with chronic conditions. The aim is to obtain reliable data on the type, nature and intensity of the care and support role and the number of these young people.

### **“Ageing at home”**

Society and those responsible for healthcare policy are faced with various challenges due to demographic change and pharmaceutical progress. This is why innovative approaches to healthcare need to be adopted in practice. The focus is on research and development projects concerned with living arrangements in private households rather than on special living arrangements, and with involving all those providing support – as opposed to professionalisation alone:

- Systematic collaboration in terms of interprofessional practice with those concerned, relatives and neighbours (e.g. *assessments regarding the development of elderly-friendly districts, integrated care networks and a new funding approach towards care*).
- Providing help via *digital platforms* and *time exchange models* beyond traditional volunteer and professional work.
- The use of technology for the elderly (new: three-country consortium known as *IBH-Lab Active and Assisted Living*).

### **“work & care”**

Careum Research is the first research institute in Switzerland to look at the compatibility of paid work and care for relatives. The research and development programme known as “work & care” has been running since 2007. The projects are concerned with social trends, the care system and work. The results promote awareness of the problems and encourage people to come up with practical offers and solutions for both employers and employees. The following main areas of focus are currently under investigation:

- The binational *project known as “Distance Caregiving”* is researching how help and care may also be delivered remotely (joint project with “Ageing at home”). The focus is on relatives providing care and their employers, as well as on elderly people being cared for at home.
- The *“Double-Duty Caregiving” project* highlights the dual role of those health professionals who look after relatives in addition to their paid work.
- The platform [www.workandcare.ch](http://www.workandcare.ch) provides access to video articles, publications and information on good practice about the compatibility of paid work and care for relatives.
- Organisational online survey: this tool enables Careum Research, on behalf of employers, to survey the “work & care” situation in their organisation.

### **“Care Migration”**

The long-term care sector is experiencing a trend towards transnationalisation: immigrants in care roles are caring for and supporting people who need assistance in private households around the clock. This is why Careum Research has developed a *guide to the day-to-day practical aspects of assistance and care at home*. In *Obsan report 57*, the phenomenon has been highlighted from the perspective of relatives and experts. Further projects on transnationalisation are planned.

### **Competence centre for patient education**

The competence centre focuses on the life of people with chronic conditions and disabilities and that of their relatives. The aim is to encourage them to become involved in the health care process. The following main topics and activities are treated:

- 1) Highlighting developments and trends relating to patient involvement and competence.
  - 2) Conducting participative and user-centred research on care.
  - 3) Development of educational services with academic support.
- This will make it possible to improve care from the perspective of patients and their relatives and provide support in terms of health literacy and self-management. Particular attention is paid to promoting equal opportunities in terms of health care:
- Introduced in 2010–2014, the Chronic Disease Self-Management Program (CDSMP) from Stanford University (USA) is adapted and used in Switzerland and the German-speaking regions of Europe as the *Evivo course programme “Living a healthy and active life”*.
  - Research work is currently being conducted on the effectiveness of self-management programmes for specific target groups such as migrants (Evivo Migration) and women with breast cancer (COSS).

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