

#### **EQUIPPING, ENABLING AND EMPOWERING**

# Global priority research agenda for improving access to high-quality affordable assistive technology





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### **Executive summary**

The World Health Organization (WHO) estimates that more than one billion people are in need of one or more assistive products. The majority of these are older people and people with disabilities. With populations ageing and a rise in noncommunicable diseases, the number of people needing assistive products is projected to increase to beyond two billion by 2050.

However, only one in ten people in need currently have access to assistive technology. Without access, people are often excluded and may be locked into poverty and isolation; increasing the impact of disease and disability on the person, their family and on society as a whole. To address the substantial gap between the need for and provision of assistive technology, WHO established the Global Cooperation on Assistive Health Technology (GATE). The GATE initiative has prioritized research and innovation as a key focus area.

To promote research and innovation, WHO established a core group to identify strategic research priorities for the GATE initiative and called for a GATE Research Group meeting in Budapest in September 2015. The core group members are experts from the Association for the Advancement of Assistive Technology in Europe (AAATE), the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), Zuyd University of Applied Science, and Trinity College Dublin.

Core group members consulted 50 experts from 25 countries to invite contributions to the priority research agenda for the Budapest meeting. Following this, 64 experts from 25 countries took part in a GATE Research Group consensus meeting and identified five global priority research thematic areas as essential to improving access to high-quality affordable assistive technology:

- 1. Effects, costs and economic impact of assistive technology.
- 2. Assistive technology policies, systems, service provision models and best practices.
- 3. High-quality and affordable assistive technology.
- 4. Human resources for the assistive technology sector.
- 5. Standards and methodologies for the assessment of assistive technology need and unmet need.

Meeting participants also arrived at a consensus on two guiding principles for any assistive technology-related research activities:

- 1. User involvement in all aspects of research, especially on policy and service provision.
- 2. Work from a social and environmental model of disability and participation.

The main purpose of the current report is to share the resulting global priority research agenda and to invite researchers, states, donor agencies, user groups, civil societies and other stakeholders to initiate/support research activities that contribute to closing the gap between global assistive technology need and unmet need.



## Why a global priority research agenda?

Assistive technology refers to assistive products and related systems and services developed for people to maintain or improve functioning and thereby to promote well-being. It enables people with difficulties in functioning to live healthy, productive, independent and dignified lives, participating in education, the labour market and social life. Assistive products are essential tools: to compensate for an impairment or loss of intrinsic capacity; to reduce the consequences of gradual functional decline; to reduce the need for carers, for primary and secondary prevention; and to help rationalize health and welfare costs. Without access to assistive products, people in need are often excluded and may be locked into poverty and isolation (1).

The World Health Organization (WHO) estimates that there are currently more than a billion people who could benefit from access to one or more assistive products. With populations ageing rapidly and as the prevalence of noncommunicable diseases rises across the world, estimated needs are expected to rise above 2 billion by 2050, with many older people needing two or more products as they age (2,3). Ageing is typically associated with a gradual decrease in physical and mental capacity, as well as a growing risk of disease. However, these changes are neither linear nor consistent, and are only loosely associated with a person's age in years (4). This presents both challenges and opportunities for supporting people with assistive technology in order to sustain independent, productive and healthy lives.

Those who most need assistive technology include, among others: people with disability, older people, people with noncommunicable diseases, people with mental health conditions including dementia and autism, and people with gradual functional decline. WHO also estimates that only 1 in 10 people in need currently have access to assistive technology, owing to a lack of financing, availability, awareness, trained personnel and high costs (5). For example, 70 million people are estimated to need wheelchairs, but only between 5% and 15% have access to one. Hearing aid production is thought to meet only 10% of global need and 3% of the need in lowincome countries (6).

Increasing access to assistive technology – and closing the gap between need and unmet need – is an urgent global necessity. If we do not substantially change the current situation this gap will increase, further marginalising those without access to quality assistive technology and undermining their ability to be productive and enjoy fundamental human rights (7).

The United Nations (UN) has recognized and acknowledged poor access to assistive technology as a critical problem to address. *The Convention on the Rights of Persons with Disabilities* entitles all people to available and affordable assistive technology, and stipulates that states should take effective measures to enable access to such technology (7). Increasing access to high-quality and affordable medical products, which includes assistive products, is also one of the six leadership priorities of WHO.

It was in this light that WHO launched the Global Cooperation on Assistive Technology (GATE) in 2014. GATE is an assistive technology stakeholder platform, which aims to improve access to high-quality affordable assistive products as an integral part of responding to the call for access to essential, high-quality, safe, effective and affordable medical products (8). To promote research that contributes to achieving this aim, GATE has developed a global priority research agenda through a global consultation and consensus process.

## How was the global priority research agenda developed?

This research agenda was developed through the following six steps:

- Online questionnaire.
- II. GATE Research Group consensus meeting, in partnership with other key stakeholders.
- III. Follow-up meeting.
- IV. Drafting of an initial priority research agenda.
- V. Peer review and feedback.
- VI. Finalization of priority research agenda.

Experts from all WHO regions participated in the process, as summarized in Appendix 1.

### I. Online questionnaire

An online questionnaire with 12 items was developed to identify possible global research priorities within the field of assistive technology (Appendix 2). An invitation to complete the questionnaire was sent to 79 experts who were identified through purposive sampling within relevant WHO and author networks, and through referral (or 'snowball') sampling.

Fifty responses were received, of which 35 comprised personal opinion and 15 were submitted on behalf of one or more organizations (Appendix 3). Forty-four responses were received from countries classified by the World Bank (9) as high-income, four were from middle-income countries, and two were received from low-income countries (see Appendix 1). Responses were received from a broad range of technical disciplines and specializations. Despite all efforts, responses from low- and middle-income countries were very limited, possibly reflecting the current status of access to assistive technology.

#### II. GATE Research Group consensus meeting

At the request of WHO, the first meeting of the GATE Research Group was organized on 9 September 2015, hosted in Budapest (Hungary) by the Association for the Advancement of Assistive Technology in Europe (AAATE). AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), Trinity College Dublin Centre for Global Health and Zuyd University of Applied Sciences were actively engaged in co-organizing the meeting.

Nearly 100 representatives of international organizations/universities, researchers and experts in the field of assistive technology were invited to the meeting. A total of 64 experts from 20 high-income countries, four middle-income countries and one low-income country participated in the meeting (Appendix 1). Most of the participants had a current position or role in assistive technology research. Several occupational therapists, physical therapists, advisors and consultants representing a broader view of the related service environment also participated in the meeting. Several of the attending experts were also users of assistive products.

The meeting started with a few short presentations to set the scene; focusing on the main purpose of the meeting, and discussing the conclusions of the online questionnaire. The major data gathering function of the meeting was facilitated by four focus group discussions (as an integral part of the meeting), each sequentially discussing four broad research themes that were framed in the form of questions (see Appendix 4). The focus group discussions produced diverse ideas and opinions, which were either recorded or noted, and subsequently analysed further.

#### III. Follow-up meeting

A follow-up meeting was held the day after the GATE Research Group consensus meeting, among a sub-group of its participants. Participants were selected on the basis of a balanced geographic spread and in order to enhance a global perspective. The purpose of the follow-up meeting was to consider and consolidate the diverse array of topics highlighted during the consensus meeting into a condensed set of priority research themes and issues.

Sixteen people (from 11 countries) took part in the follow-up meeting, including four members of the organizing team. The majority had worked internationally and had research experience in low- and middle-income countries and most had a current/ previous professional role in assistive technology research. Several of the attending experts were also users of assistive products.

### IV. Drafting of initial priority research agenda

Based on the results from steps I-III, the core group received 256 diverse research suggestions/views. After thorough analysis, these were broadly categorized into five thematic areas, as follows:

- 1. The effects, costs and economic impacts of assistive technology.
- 2. Policies, systems, service provision models and best practices.
- 3. Development of high-quality and affordable assistive technology.
- 4. Capacity building and human resource deployment for assistive technology services.
- 5. Development of standards and methodologies for the assessment of basic assistive technology-related needs.

For each thematic area, the core group proposed a consolidated set of key research questions that were representative of the research suggestions/views raised during steps I-III. The thematic areas and the underlying key research questions formed the basis of an initial draft priority research agenda.

#### V. Peer review and feedback

All participants in steps I-III were asked to provide feedback on the draft research agenda. Forty-four received responses were all supportive of five thematic areas, helping to authenticate their validity, and offered constructive comments for improving the draft text/key research questions.

#### VI. Finalization of global priority research agenda

Based on the feedback received, the following five global priority research thematic areas were updated and finalized:

- 1. Effects, costs and economic impact of assistive technology.
- 2. Assistive technology policies, systems, service provision models and best practices.
- 3. High-quality and affordable assistive technology.
- 4. Human resources for the assistive technology sector.
- 5. Standards and methodologies for the assessment of assistive technology need and unmet need.

## What is the global priority research agenda?

When compared with other medical or health products, the evidence base demonstrating the efficacy and impact of assistive technology is relatively weak, particularly in relation to cost-benefit analyses. WHO considers assistive products to be essential tools: to compensate for an impairment or loss of intrinsic capacity; to reduce the consequences of gradual functional decline; to reduce the need for carers, for primary and secondary prevention; and to help rationalize health and welfare costs – a game-changer for better health and well-being.

WHO further regards the impact of assistive technology as reaching far beyond the benefits of health and well-being of individual users and their families. It also has socioeconomic benefits, by reducing direct health and welfare costs (such as hospital admissions or state benefits), enabling a more productive labour force, and stimulating economic growth. However, more research and evidence are needed to encourage policy-makers and donors to invest in the assistive technology sector, thereby ensuring that the remaining 90% of the estimated population in need (900 million now and 1.9 billion by 2050), have access to assistive technology.

Following the consultation process previously outlined, five thematic areas emerged as major global assistive technology research priorities, around which there was clear consensus:

- 1. Effects, costs and economic impact of assistive technology.
- 2. Assistive technology policies, systems, service provision models and best practices.
- 3. High-quality and affordable assistive technology.
- 4. Human resources for the assistive technology sector.
- 5. Standards and methodologies for the assessment of assistive technology need and unmet need.

These five thematic areas reflect priorities from a global perspective, incorporating those of high-, middle- and low-income countries. In responses to the step I questionnaire, other topics were highlighted that may be more relevant from a local/national perspective, but represent less of a global priority. Similarly, readers of the current report are encouraged to interpret the global priority research agenda in relation to the needs and realities of their own contexts.

In the following, the identified global priority research thematic areas are described in more detail, as well as some specific underlying key research questions arising from them.

### Effects, costs and economic impact of assistive technology

There is only limited evidence about the impact of assistive technology on people's quality of life, and about associated costs and benefits to society (including economic benefits) of fewer people living with a disability. Although this impact often seems self-evident in individual situations, evidence on a population level is lacking. Such evidence is important to motivate countries to develop or improve policies and systems for the provision of assistive products.

Research questions related to this thematic area include:

- 1.1 What are the societal and economic impacts (e.g. return on investment) of assistive technology?
- 1.2 What is the impact of assistive technology on the quality of life of people with disability?
- 1.3 What are the costs of providing assistive technology relative to outcomes?
- 1.4 What are the costs of not providing assistive technology or providing it badly?
- 1.5 What is the impact of the most needed assistive products?
- 1.6 Which assistive products are the most cost-effective?

### 2. Assistive technology policies, systems, service provision models and best practices

There are many different possible policies, systems and service provision options for assistive technology. Little is known about which ones are the most effective and efficient approaches. Many countries do not have relevant policies and systems in place at all. Evidence of what good practices exist and the most suitable approaches in given situations are important in order for countries to develop or improve policies, service provision systems and models. The development of quality standards may greatly help government agencies and service providers improve the impact of their assistive technology policies, systems and procedures.

Research questions related to this thematic area include:

2.1 What should be the key components of a framework for developing national assistive technology policy?

- 2.2 Which service provision models currently exist, what is their quality, and what is known about their impacts and outcomes?
- 2.3 What is good quality assistive technology service provision, what are best practices in this field and what are their key characteristics? How can such best practices be used to develop quality standards and guidelines?
- 2.4 How can information about service provision models and best practice solutions be made known to people who can implement them and to other relevant stakeholders?
- 2.5 How can the role of the end-user be facilitated and maximized in the service provision process (including in the design, implementation and leadership of the services)?

#### 3. High-quality and affordable assistive technology

Increasing the availability of high quality and affordable assistive technology is vital to the ambitions of the GATE initiative. The trend in high-income countries is towards high-tech solutions with optimal functionality, while in middle- and low-income countries (but increasingly also in high-income countries) there is a need for more affordable, easily available and robust products and services. Paradoxically, while most research and innovation is focused on high-tech, costly products and complex services, little attention is given to developing robust, affordable but high-quality assistive products for which there is a much greater need. This situation is leading to an increasing 'assistive technology divide', comparable to what is often referred to as the 'digital divide': wherein technologies develop rapidly and new options become available, but the majority of the world does not benefit from them.

Research questions related to this thematic area include:

- 3.1 What types of assistive products are most needed, which ones have demonstrated most benefit to users?
- 3.2 How can high-quality assistive products be made available in the most costefficient way?
- 3.3 What do industry and others need to do to satisfy the need of different income groups or countries (e.g. those with different GDP per capita)?
- 3.4 How can the maintenance and repair costs of assistive products be kept as low as possible?
- 3.5 How and to what extent can pervasive design principles and/or technological standards help to develop high-quality, low-cost solutions?

### 4. Human resources development for the assistive technology sector

Knowledge about available assistive products, the optimal match between assistive products and individual needs, and regarding the appropriate and efficient use of assistive products is essential for professionals in health care, vocational rehabilitation, education and social work to be able to provide quality advice. Technical knowledge is also essential for the development of new assistive products and to improve/service existing ones. As a result of these combined factors, there is a need to formulate and establish standards and training programmes for professionals working in assistive technology. The focus and required content of such programmes is not self-evident.

Research questions related to this thematic area include:

- 4.1 Which competencies are essential for assistive technology professionals and how can these capabilities be optimally developed?
- 4.2 What are the cost-efficient opportunities to educate professionals at various levels of capability, from basic knowledge up to high-level expertise?
- 4.3 How can information about available solutions be made known to professionals involved in the service provision process, as well as others providing services for people with impairments?
- 4.4 How can users/user groups be involved or engaged in meeting the huge deficiencies in assistive technology personnel worldwide?
- 4.5 Is it possible to develop a standardized curriculum for professionals involved in assistive products provision?

### 5. Standards and methodologies for the assessment of assistive technology need and unmet need

The demand and need for assistive technology in a given country are dependent on a large number of intricately related factors, such as available resources, the economic situation, the natural environment, the composition of the population, and many other factors. Instruments and tools are required to help analyse such factors and identify potential policies and actions that can improve the accessibility and optimal use of assistive products. Such instruments and tools are needed on different levels: national, regional and local government, among service providers, and by individuals living with a disability.

Research questions related to this thematic area include:

- 5.1 How can accurate data about the prevalence of impairments/disability be collected and used in a standardized, valid and reliable way, so that governments and service providers can plan and operate effectively?
- 5.2 How can the individual needs of people with impairments/disability be assessed and connected to the most appropriate assistive technology solutions?
- 5.3 What are the essential components of assistive technology needs assessment tools?
- 5.4 How to map coverage and user's satisfaction rates?
- 5.5 How to map the global assistive technology scenario?

#### General guiding principles

During the GATE Research Group consensus meeting, there was agreement about two general principles that are most important for all research initiatives in the field of assistive technology. The first principle is the need for *user involvement* in all aspects of research, as well as in policy development, system design and service provision. The second principle is the need to work from an *environmental approach* to functioning, instead of following a typical medical model. These two principles need to be kept in mind when addressing related research priorities. Operationalizing the principles may, in itself, require specific research.

### What is next?

This global priority research agenda is an invitation to all stakeholders to initiate and or support research that addresses identified global priority research questions. By doing so, they will contribute to bridging the gap between assistive technology need and unmet need, and closing the divide between those who can access assistive technology on the basis of wealth rather than according to actual need. The suggested global research priorities are broad and within each thematic area a large number of relevant research questions can be addressed. The authors have deliberately chosen not to present all the related research questions; each researcher or research group will need flexibility to tune research questions to specific priorities and needs in their own setting. In the spirit of offering a guide, it is nonetheless hoped that research in the field of assistive technology will converge towards the main thematic areas proposed in this document.

The priority global research agenda is not only highly relevant from a societal perspective, it is also scientifically challenging. There is a conspicuous lack of quality research and evidence for many of the thematic areas and new methodologies will have to be developed. Researchers, as well as professional and scientific organizations in the field of assistive technology, will take up the challenge and work together in stimulating and executing international research as described in this agenda. Finally, this agenda also presents great opportunities for industry. The market potential is huge for developing and producing the right products at affordable cost. The GATE Research Group envisages innovative and exciting collaborations arising to implement this global priority assistive technology research agenda, and to bring much needed assistive products and services to those in need.

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### Participating experts by country

Number of participants in each event by their country of origin.

Country	Online questionnaire	GATE Research Group meeting	Follow-up meeting
1. Australia	4	2	1
2. Austria	1	1	
3. Belgium		2	1
4. Brazil	1	1	
5. Cambodia	1		
6. Canada	5	5	2
7. Colombia	2		
8. Cyprus	1	1	
9. Denmark	1	2	
10. Egypt		1	
11. Finland	1	1	
12. France		3	
13. India	1		1
14. Ireland	2	3	1
15. Israel	1		
16. Italy	2	2	
17. Japan	1	1	1
18. Namibia	1	1	
19. Netherlands	1	4	2
20. Norway	2	3	
21. Pakistan		1	
22. Romania	1		
23. South Africa		3	2
24. Republic of Korea	1	2	
25. Spain	1	1	
26. Sweden	3	3	1
27. Switzerland		4	1
28. Taiwan, China	1		
29. United Kingdom	2	5	
30. United States of America	20	17	5
31. Zimbabwe	2	1	
Total, countries	25	25	11
Total, participants	50	64	16

### Questionnaire to set the research meeting agenda

- 1. What is your name?
- 2. What is your email address?
- 3. Do you respond in a personal capacity or on behalf of an organization?
- 4. What is your professional background?
- 5. What is your current role or position in the field of assistive technology?
- 6. In which country do you live and work?
- 7. What are, in your opinion, the <u>five</u> most important areas of human functioning (in terms of the ICF; activity and participation) for which assistive technology is needed in your country?
- 8. What are, in your opinion, the **three** most important areas of functional needs in the elderly population in your country, which might require assistive technology?
- 9. What do you consider the research priorities regarding assistive technology in the following domains:
  - a. Health:
  - b. Education:
  - c. Policy:
  - d. Economy:
  - e. Culture:
  - f. Environment:
  - g. Awareness:
  - h. Outcomes and effects:
  - i. Employment:
  - j. Others:
- 10. If you had to prioritize three assistive technology topics for research, which would these be?
- 11.Do you have any additional comment or suggestion?
- 12. Do you wish to participate in the GATE Research Group meeting?
  - a. No
  - b. Yes: name, organization, email

#### Organizations responding to the questionnaire

- 1. AGE-WELL NCE Inc, Canada
- 2. Australian Rehabilitation & Assistive Technology Association (ARATA)
- 3. Dong-Eui University, Republic of Korea
- 4. Elsaesser Consulting Inc, USA
- 5. European Disability Forum (EDF), Belgium
- 6. Lund University, Sweden
- 7. Physical and Rehabilitation Medicine Department, School Of Medicine, University of São Paulo, Brazil
- 8. R2D2 (Rehabilitation Research Design & Disability) Center, USA
- 9. Raising the Floor International (RtF)
- 10. Rehabilitation Engineering and Assistive Technology Society of Korea (RESKO)
- 11. Rehabilitation Engineering Society of North America (RESNA)
- 12. Skandinavias største uavhengige forskningskonsern (SINTEF), Norway
- 13. The Centre of Expertise of Innovative Care and Technology (EIZT), Netherlands
- 14. Trace R&D Center, USA
- 15. University of Colorado, Department of Bioengineering, USA
- 16. University of Pittsburgh, USA
- 17. University of Sao Paula, Brazil
- 18. University of Wisconsin-Madison, USA
- 19. University of Wisconsin-Milwaukee, USA
- 20. World Federation of Occupational Therapists (WFOT)

### Programme of the GATE Research Group meeting

The meeting will take place during the preconference of AAATE 2015, on September 9 2016, from 13.00 until 18.00 in the Budapest Congress Centre (Jagello u. 1–3), Liszt Room.

13.00	Arrival and light lunch
13.30	Opening by Chapal Khasnabis, WHO
13.45	Introduction remarks by presidents of AAATE (Evert-Jan Hoogerwerf) and RESNA (Ray Grott)
13.55	Presentation of the results of the online questionnaire by Luc de Witte, Zuyd University of Applied Sciences
14.10	Systems Perspectives, BEAT and WHO-CC concept by Trinity College Dublin Centre for Global Health (Malcolm MacLachlan)
14.20	<ul> <li>Structured discussion of 4 selected topics in small groups, in rounds of 30 minutes with 5 minutes for change of topic. The following topics were discussed:</li> <li>1. What are the critical research questions regarding identification of the facilitators and barriers, including cultural and/or contextual factors affecting the use of assistive products and services?</li> <li>2. What are the critical research questions regarding the development of successful models for the delivery, implementation and support of assistive products and services, including human resources required?</li> <li>3. What are the critical research questions regarding how assistive technology products and services and their delivery systems should be monitored and evaluated?</li> <li>4. What are the critical research questions regarding policy development promoting the provision of assistive technology products and services, including the role of different stakeholder groups?</li> </ul>
15.25	Coffee/tea break
15.40	Continued discussion in small groups
16.45	Refreshments and time for discussion leaders to wrap up results
17.00	Plenary discussion
	short presentation of findings regarding the selected topics
	discussion of further process and follow-up of the meeting
	closing remarks by Chapal Khasnabis
17.55	Closure of the meeting

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#### **EQUIPPING, ENABLING AND EMPOWERING**

## Improving access to assistive technology for everyone, everywhere

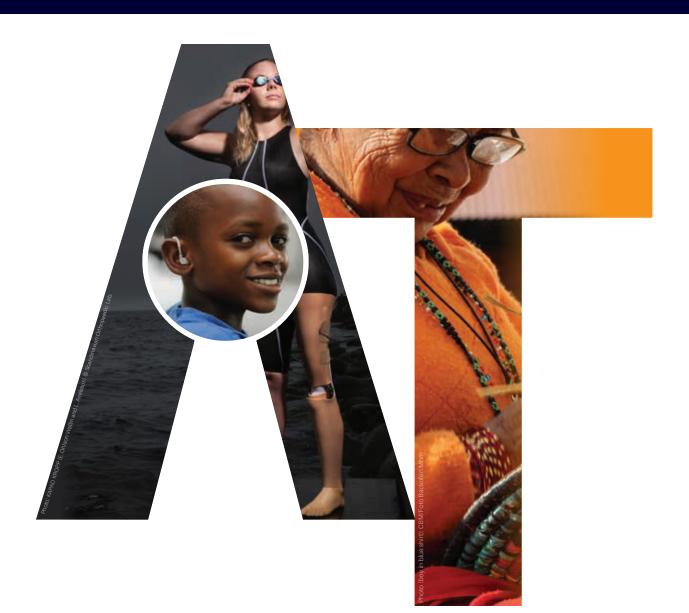


Photo (boy in blue shirt): CBM/Foto Backofen Mhm