30 years of care and rehabilitation of visually impaired adults and older people

Peter Verstraten

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30 years of care and rehabilitation of visually impaired adults and older people

- Dutch perspective
- European perspective
- Global perspective

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Personal history

- 1984 - 1988: Radboud University Nijmegen
- 1986 - 1991: Two nursing homes
- 1988 - now: Field of Visual Impairment
    * Theofaan (1988) → Sensis (2001) → Royal Dutch Visio (2010)
    * Robert Coppes Foundation (2016)

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Until the eighties

- One national rehabilitation centre in Apeldoorn:
  - 1959: De Schansenberg
  - 1976: Het Loo Erf
- One national organisation (SMDBS) for outpatient support, operating from Amsterdam

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During the eighties

- Development of regional centres, officially recognised (financed by government) since 1 January 1988

  → nowadays +/- 20 regional centres
- New residential facility: Robert Coppes Foundation (for VI adults and older people with multiple additional disabilities)

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Dutch VI rehabilitation characteristics

- Not ‘just’ a focus on employment related rehabilitation
- No age differentiation concerning accessibility to rehabilitation services
- Holistic view → ICF

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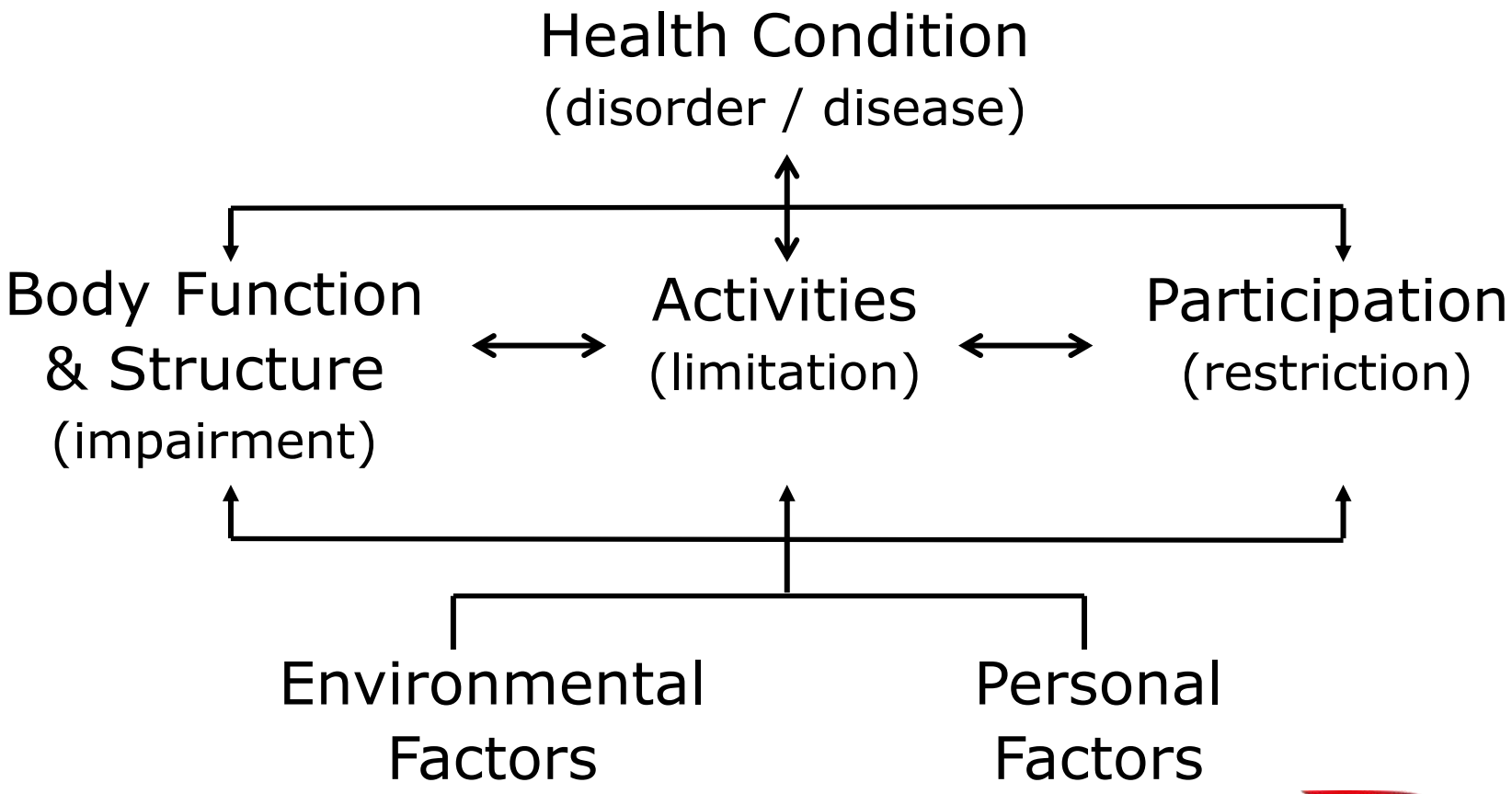
Basic structure of ICF



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ICF history in the VI field

- 1992: adaptation of ICIDH to VI field (Paul Looijestijn)
- 1996: accepted as framework and common language by Dutch VI service providers
- 2001: ICIDH → ICF
- 2007: ICF-CY

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ICF: International Classification of Functioning, Disability and Health

- Provides a systematic coding scheme for health information systems
- Permits comparison of data across:
  - Countries
  - Health care disciplines
  - Services
  - Time
- Provides a scientific basis for consequences of health conditions
- Establishes a **common language** to improve communication

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ICF useful for

- Assessing the requests and needs of the client
- Formulating rehabilitation goals
- Drawing up rehabilitation plans
- Evaluating results

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ICF-based tools in the VI field

- Visual Profile (Paul Looijestijn)
- PAI: Participation and Activity Inventory (Low Vision Research group at the ophthalmology department of VU University Medical Center Amsterdam)
  - Adults and older people
  - Young Adults (PAI-YA)
  - Children and Youth (PAI-CY)

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Thomas J. Carrol (1961)

Blindness. What it is, what it does, and how to live with it

- Psychological Security
- Losses and Restorations in Basic Skills
- Communication and Information
- Losses and Restorations in Appreciation
- Occupation and Financial Security
- Losses and Restorations to the Whole Personality
- Resources for Coping

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ICF: Activities and Participation

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life

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PAI

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life
- Mental health (emotional) aspects

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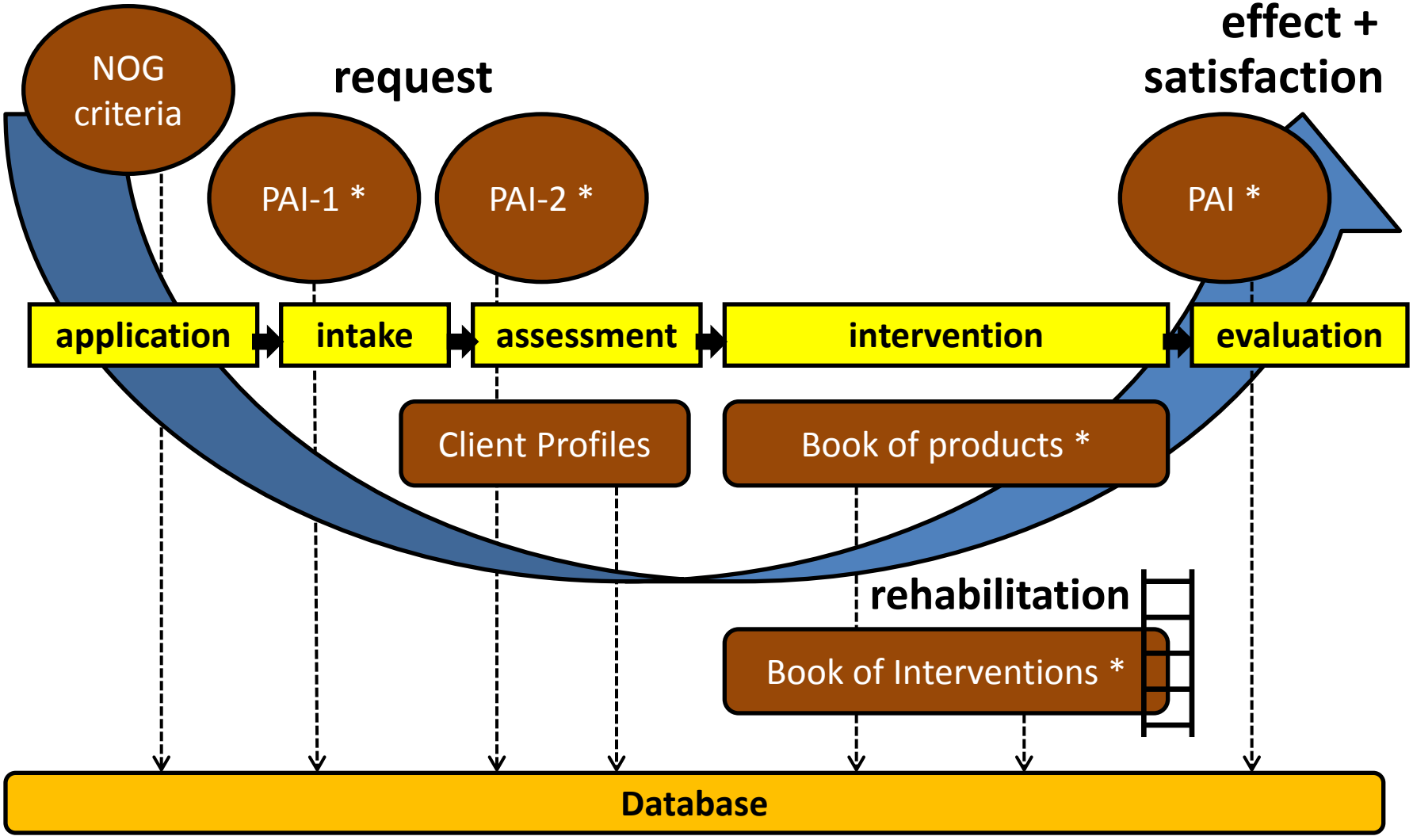
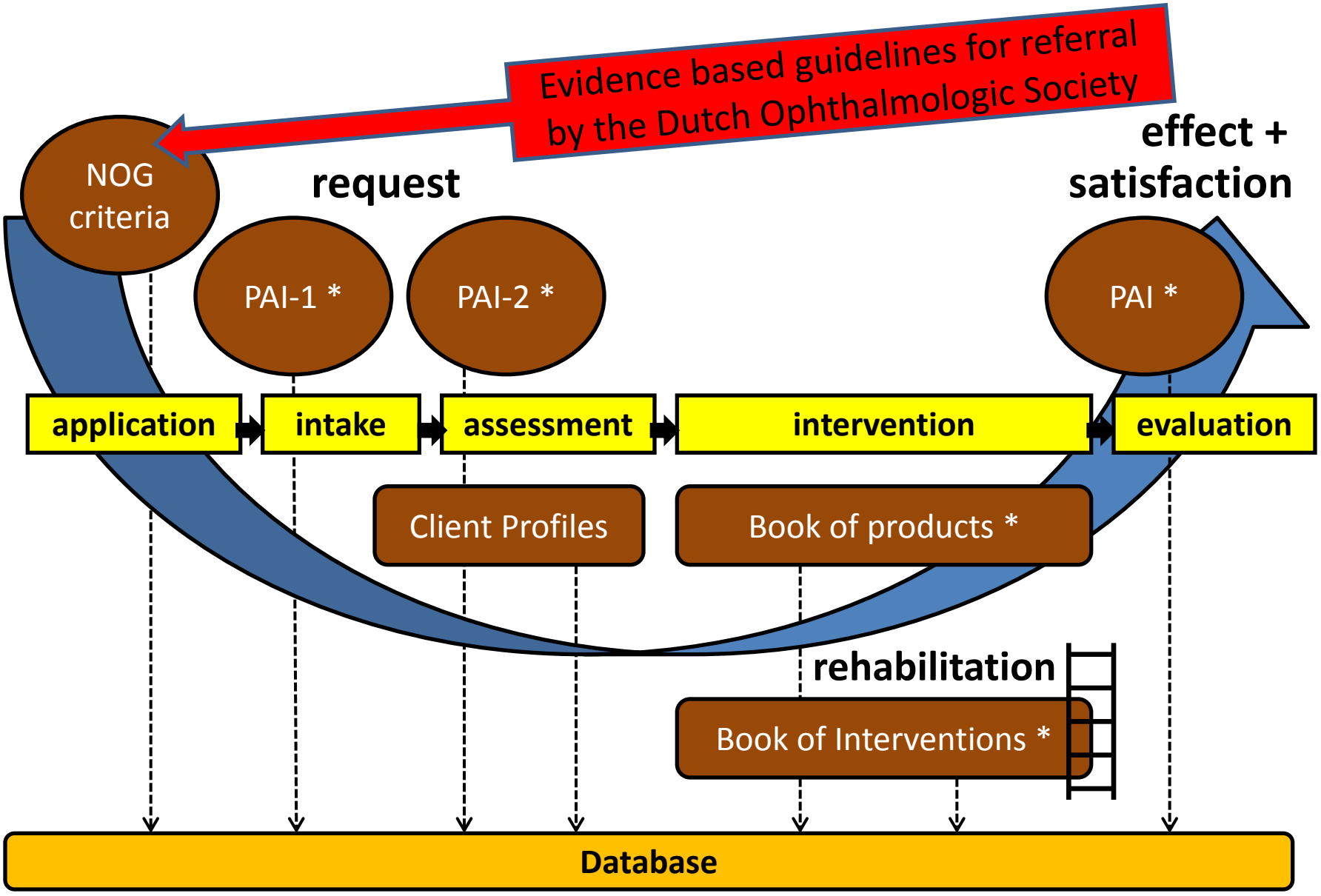

NOG criteria
request
PAI-1 *
PAI-2 *
effect + satisfaction
PAI *
application
intake
assessment
intervention
evaluation
Client Profiles
Book of products *
rehabilitation
Book of Interventions *
Database

* = based on ICF


Evidence based guidelines for referral by the Dutch Ophthalmologic Society
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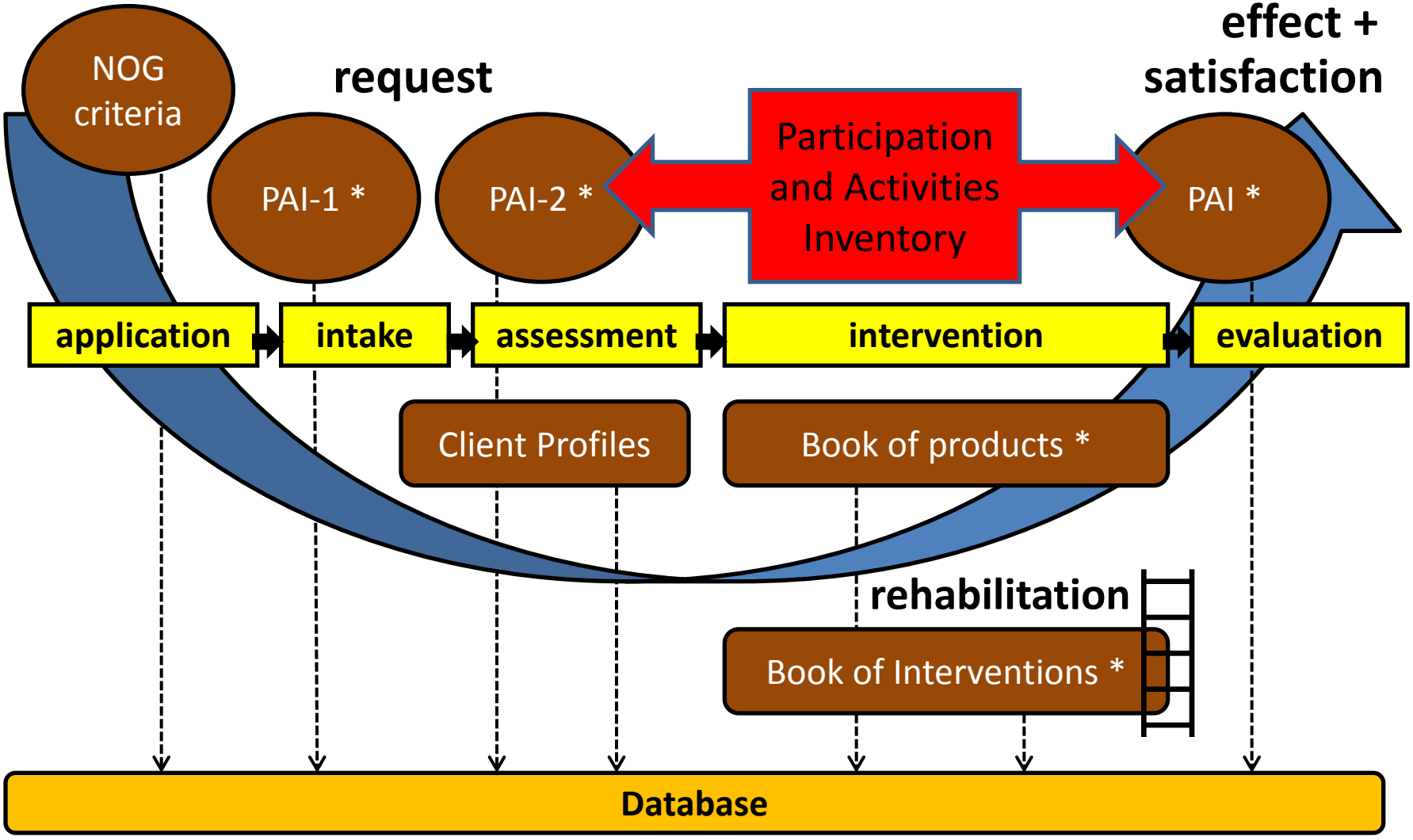
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Welcome to the Robert Coppes Foundation

Robert Coppes Stichting

Target group

Persons, age 18+, with a visual impairment and multiple additional disabilities

- mainly psychiatric impairments, but also:
- acquired brain injury
- hearing impairment
- autism
- addiction
- etc.

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Target group

Persons, age 18+, with a visual impairment and multiple additional disabilities

- mainly psychiatric impairments, but also:
- acquired brain injury
- hearing impairment
- autism
- addiction
- etc.

All with an increased psychological vulnerability and additional problems to compensate for their vision loss

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Services offered

- Residential facilities ranging from 24/7 care to supported living with professionals available just when necessary
- Day-care facilities
- Outpatient counselling based on specialised care and support, usually with intermittent treatment (= with interruptions): so-called Rehabilitative Care Program, that consist of basic care and support with training/therapy alternately

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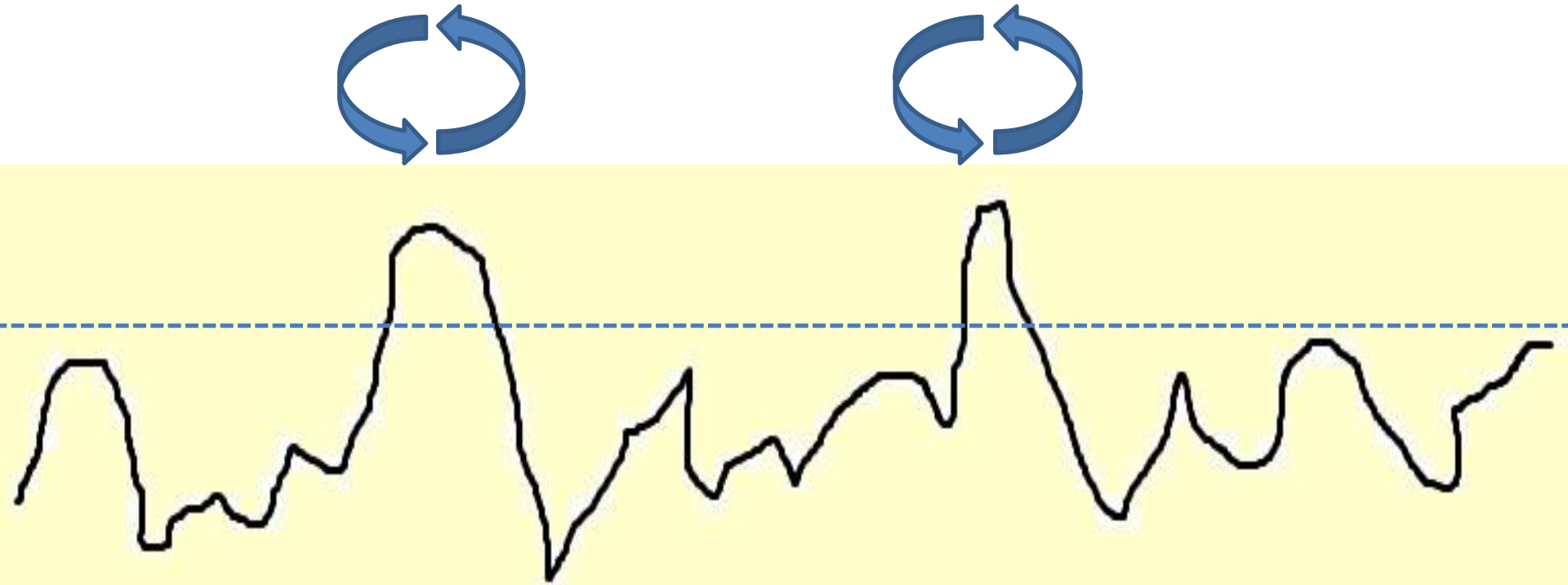
Intermittent treatment



Specialist care and support for independent living

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Professionals (12-15 pers.) at regional centres: multidisciplinary approach

- Clinical Physicist (specialised in the visual system; sometimes also audiologist)
- Low vision specialists: Optometrists / Orthoptist
- Clinical psychologists / Neuropsychologists / Social workers
- Occupational therapists / Mobility instructors / Computer instructors / Job coaches
- Officers Information & Advice

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Professional waves

- Social workers
- Occupational therapists
- Low vision specialist
- Neuropsychologists
- IT-instructors

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Element of basic rehabilitation

- Assessment of visual functions
- Psychological assessment
- Emotional support
- Development and training of the (other) senses
- Braille training
- Communication skills
- Training in the use of communication aids / computer skills training
- Training of orientation and mobility skills
- Training self care and domestic life
- Social skills training
- Leisure time training

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Intensive rehabilitation (Visio Het Loo Erf)

- Custom made
- Holistic approach
- Three anchors:
  - Intrapsychic / social emotional adaptation
  - Instrumental / technical rehabilitation
  - Participation in society / (re)integration

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Three anchors:

- Intrapsychic / social emotional adaptation
  - This refers to developing coping skills. Methods are personal coaching, group work and process-based psychosocial support
- Instrumental / technical rehabilitation
  - This refers to skills concerning living, working and learning. More concrete this is about braille, mobility, perception, communication techniques and skills, information technology, optical devices, using residual visual functions, daily living skills.
- Participation in society / (re)integration
  - Methods are personal support, group work, person-centred themes like employment, living at home, leisure or study.

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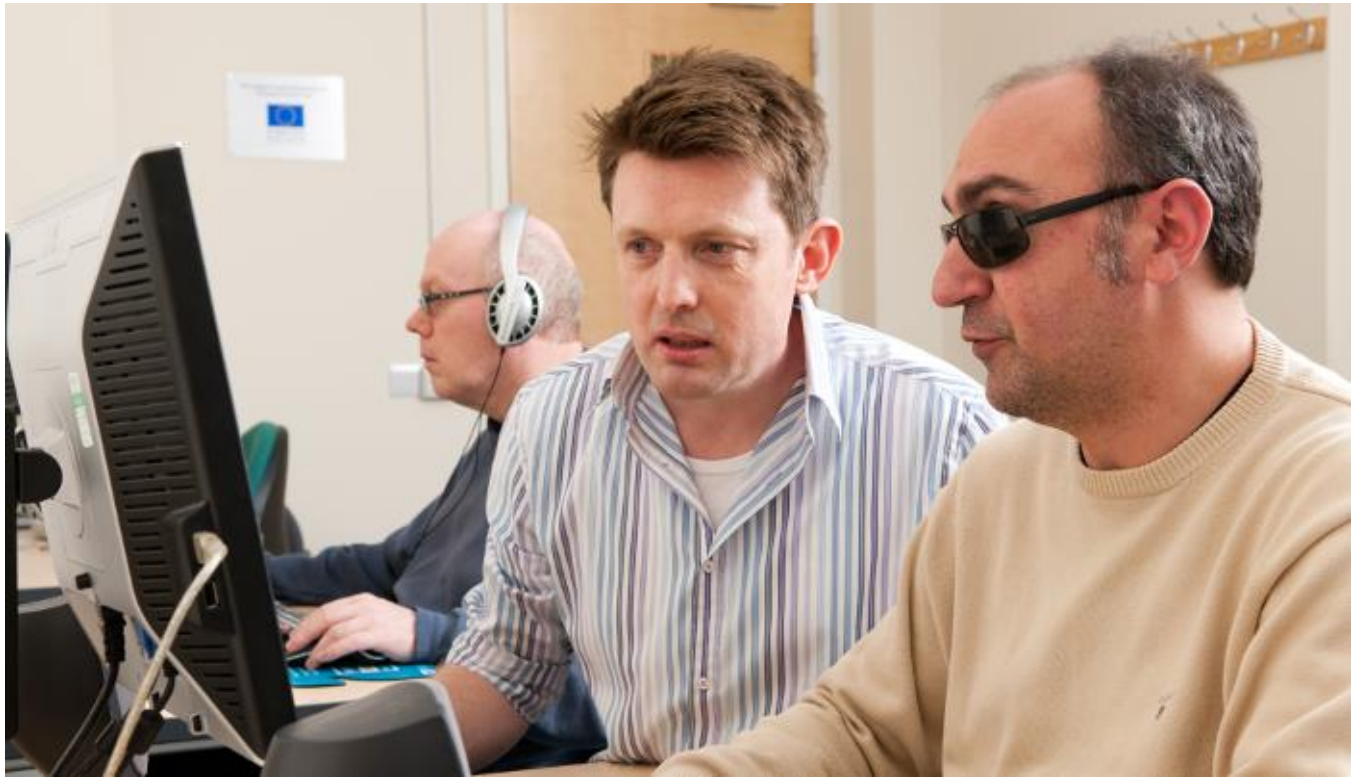
Dutch VI employment rehabilitation



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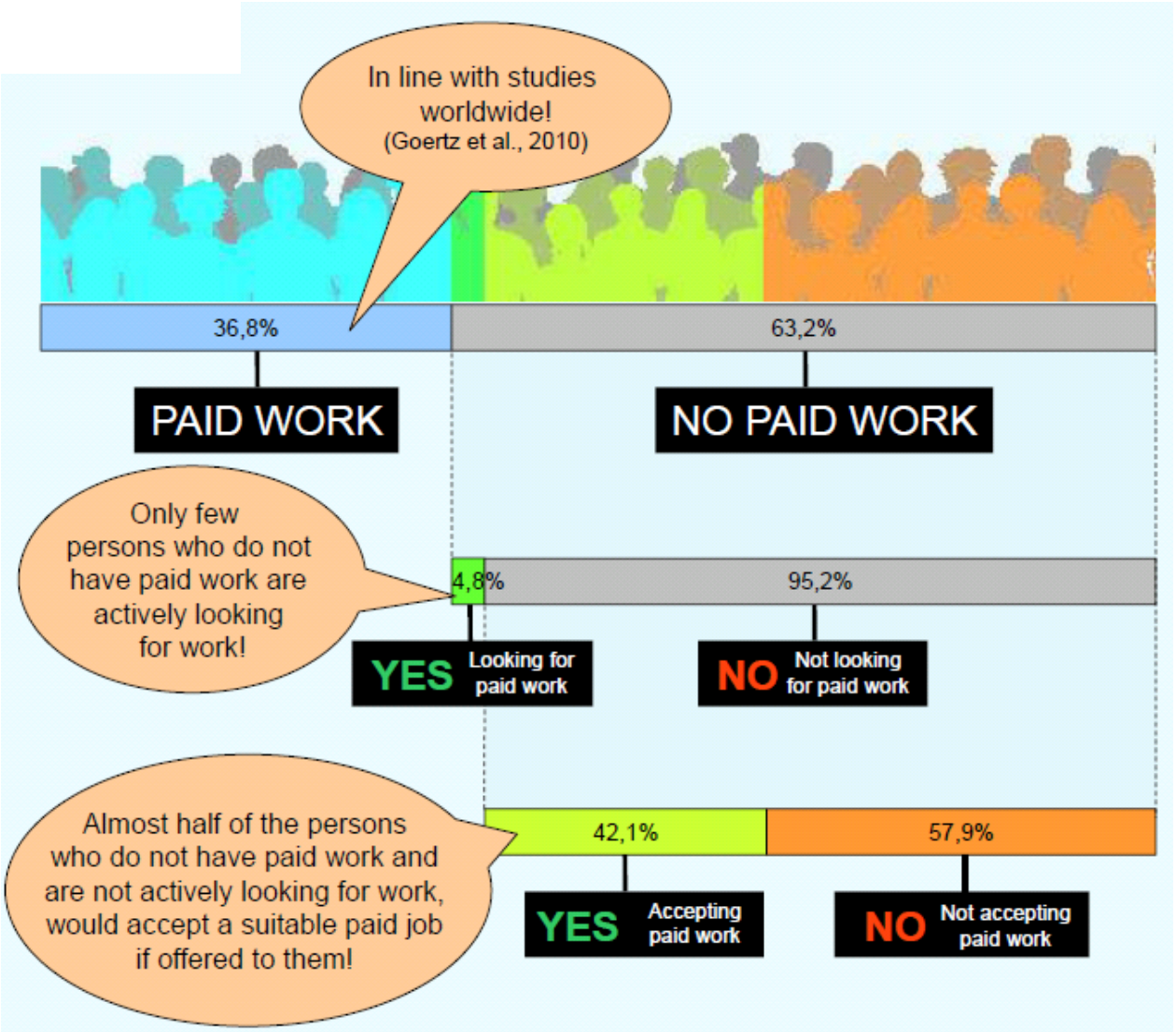
Goertz, Y.H.H., van Lierop, B.A.G., Houkes, I., Nijhuis, F.J.N. (2010) Factors related to the employment of visually impaired persons: a systematic literature review. *Journal of Visual Impairment & Blindness 104*(7), 404–418



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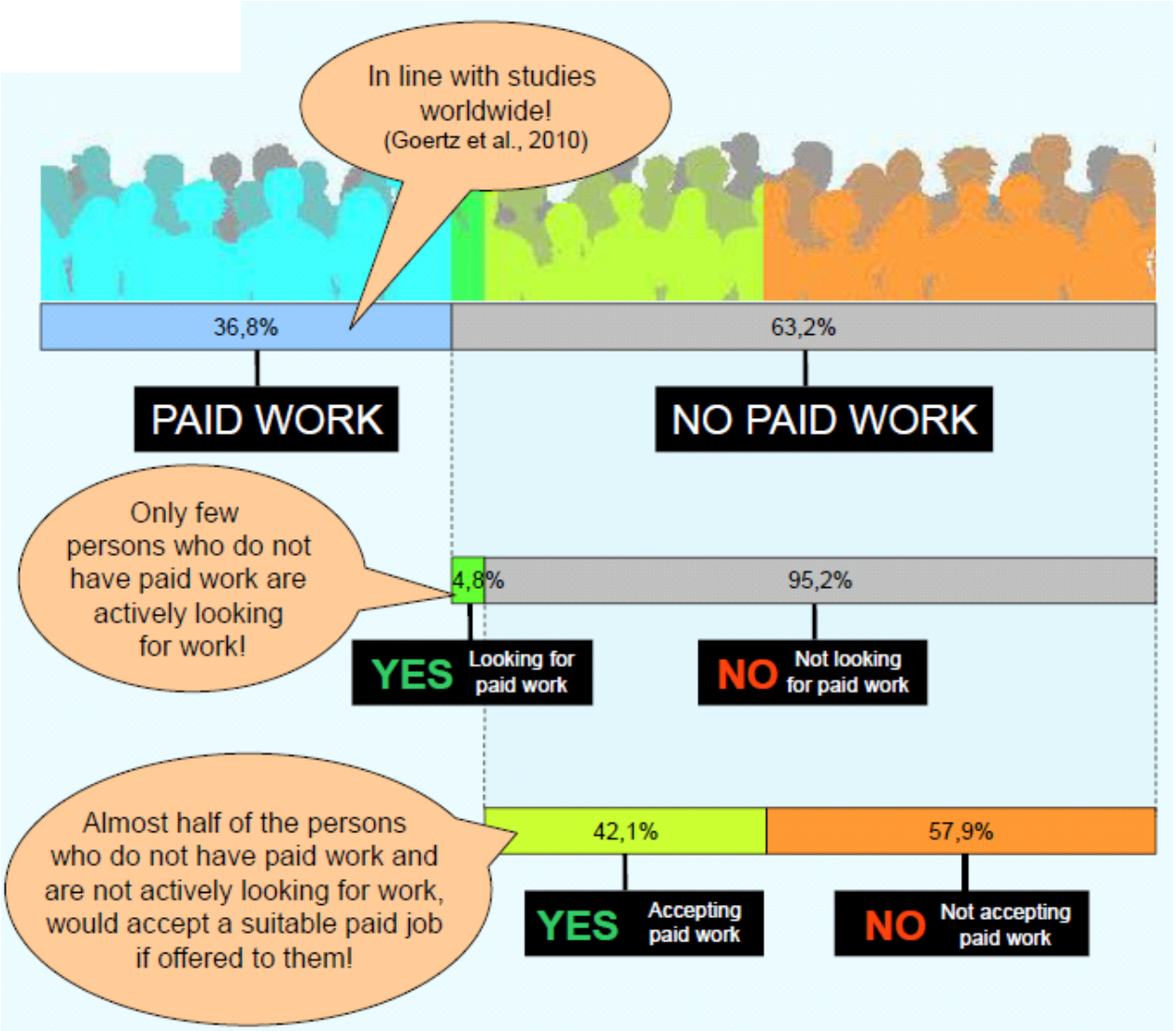

However, when not counting sheltered workshops and small jobs (< 12 hrs.) the percentage drops to 20-27%

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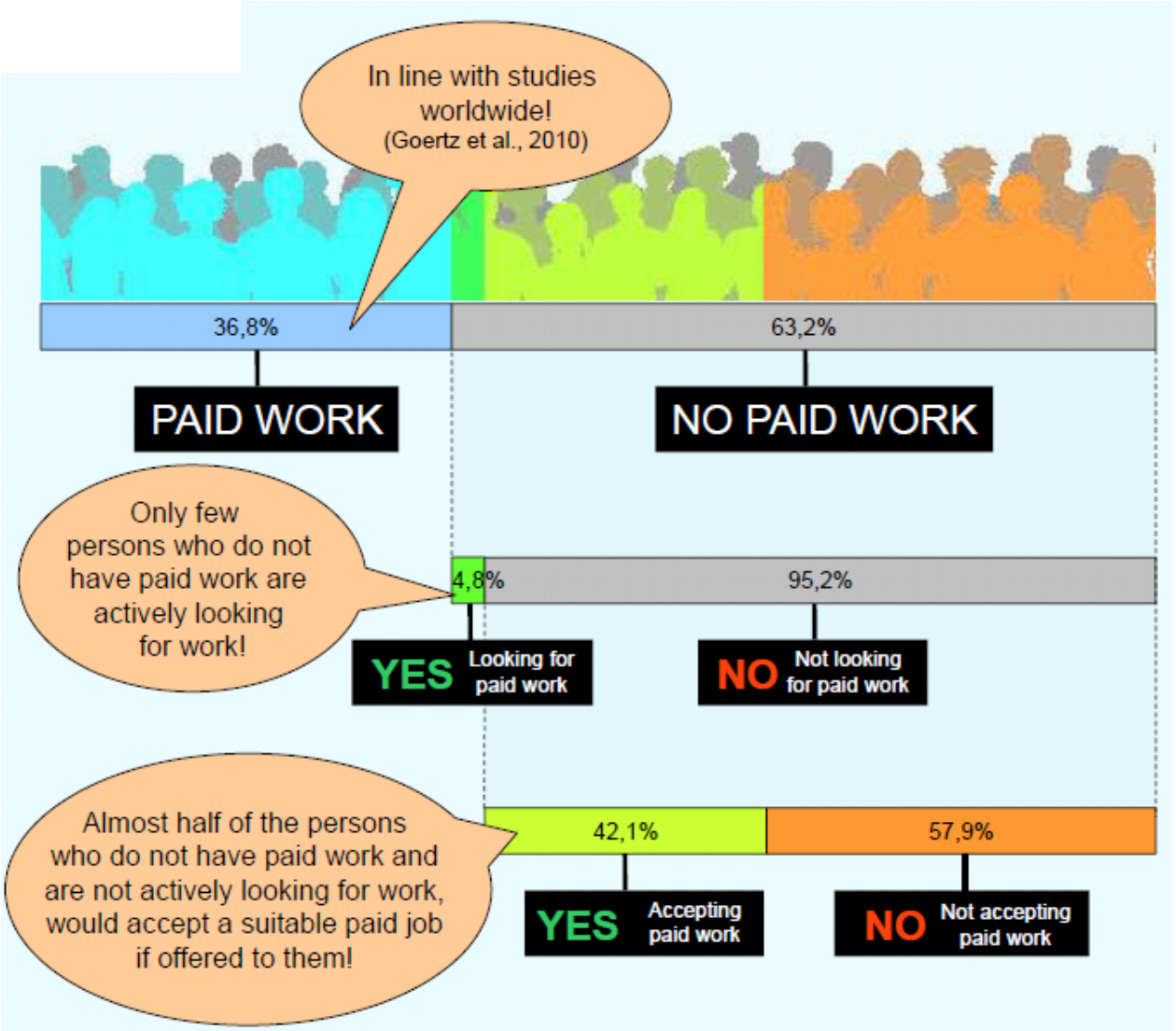
Goertz, Y.H.H., van Lierop, B.A.G., Houkes, I., Nijhuis, F.J.N. (2010) Factors related to the employment of visually impaired persons: a systematic literature review. *Journal of Visual Impairment & Blindness 104*(7), 404–418



The employment level of people with disabilities in general is 45%

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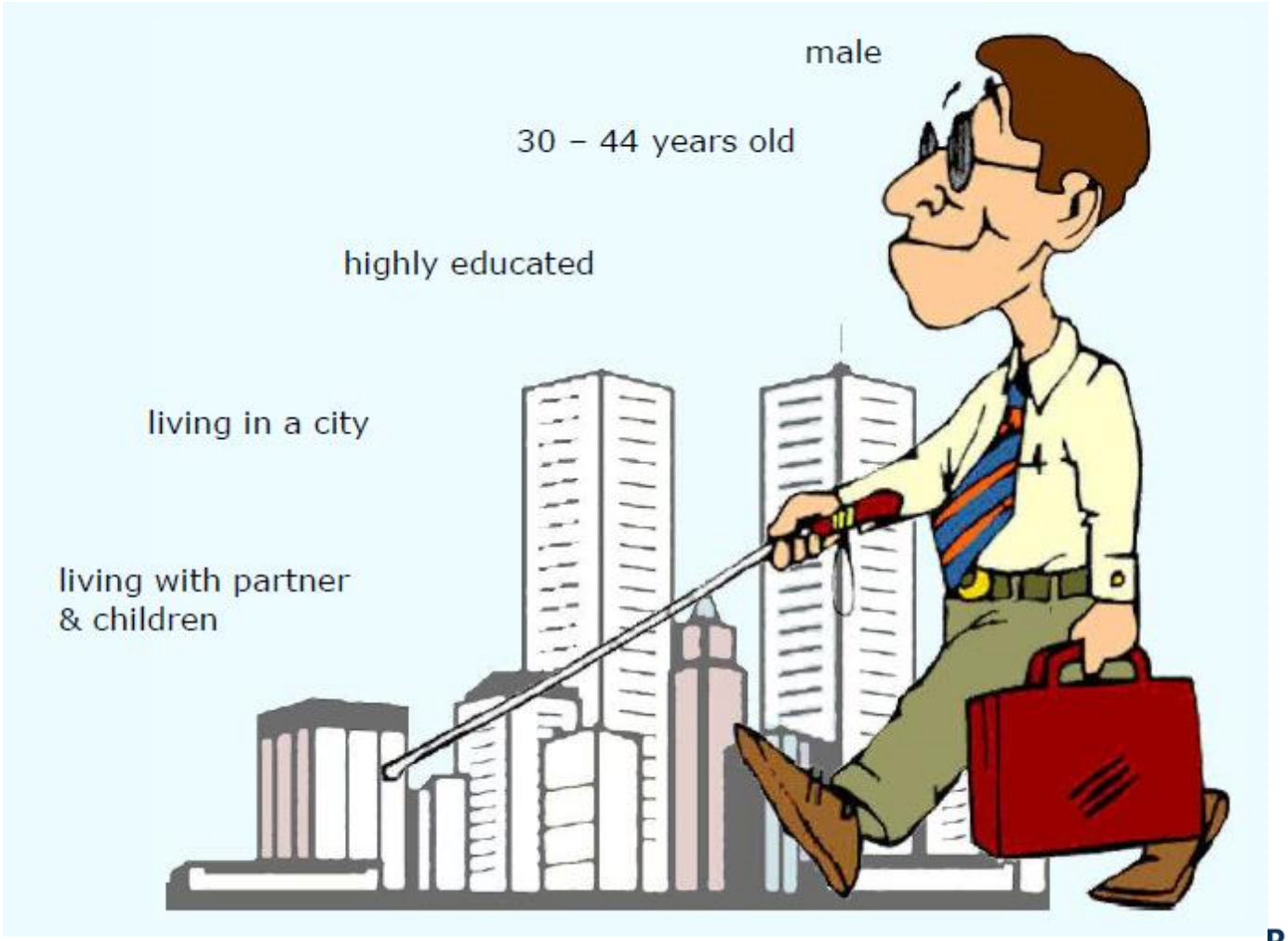
VIPs with paid work often are



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Reasons for low employment rate

- Transition from school to work is not enough organised in a structural way
- Very little expertise on VI at the regular reintegration offices
- Looking at limitations instead of talents
- Many prejudices towards VIPs at each level of society
- Working conditions not adapted
- Rather easy access to unemployment pension

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New laws

- Only access to employment pension if one can not earn > 20% of the minimum income level
- This is the case for 20% of the VI pupils who leave school
- The others are depending on local government (municipalities)
  - Minimum budget
  - Little knowledge

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Good intentions

- Government wants to create 25.000 jobs for those who can not exceed minimum wage
- Business companies want the same for 100.000 jobs
- Labour costs are subsidised
  - 40% wage
  - 60% subsidy
  - Job coaching is offered

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Specific elements of employment rehabilitation

Additional focus on (proven) success factors:

- Communication about one's own visual impairment: Presentation!
- Social skills / network skills
- Physical and emotional capacity
- Physical accessibility workplace
- Work skills (e.g. IT skills)
- Mobility skills (independent travel)

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Conclusions and recommendations of 20 years of research

Important themes in helping VIP being successful at work:

- VIP must have a realistic view of society
- VIP must have a realistic view of own personality, talents and limitations
- Increase positive image in society
- Increase knowledge about low vision
- Increase in VIP's communication skills about one's own visual impairment
- Increase level of acceptance of the visual impairment
- Focus on talents of the VIP instead of limitations

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VI older people in the Netherlands

- 79% of all visually impaired people is age 65 or older
- 85% is over age 50

→ Consequences for service providers
→ Consequences for rehabilitation professionals
→ Consequences for education of professionals
→ Consequences for research

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The needs of VI older people tend to be

- Less extensive
- More focussed
- More near to daily practice
- More oriented to concrete goals than to (more general) problem solving skills

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Multimorbidity

- Cognitive ageing
- Hearing impairment (dual sensory loss!)
- Physical condition

- In about 2/3 of older visually impaired clients there is more to it than ‘just’ vision loss
- Therefore cooperation with other service providers is often required → care chain

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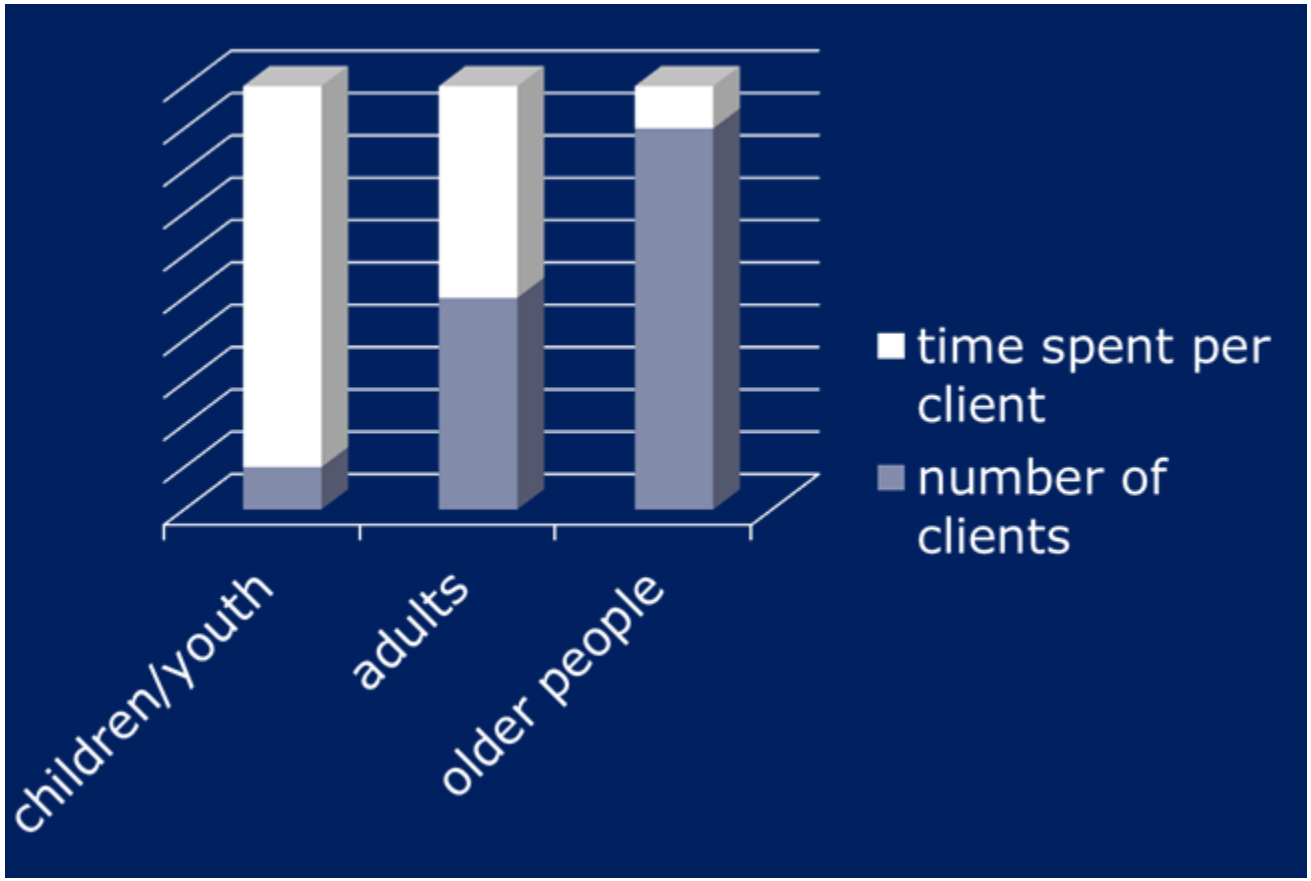
Older visually impaired clients: 79% of the people or 1/3 of the ‘production’



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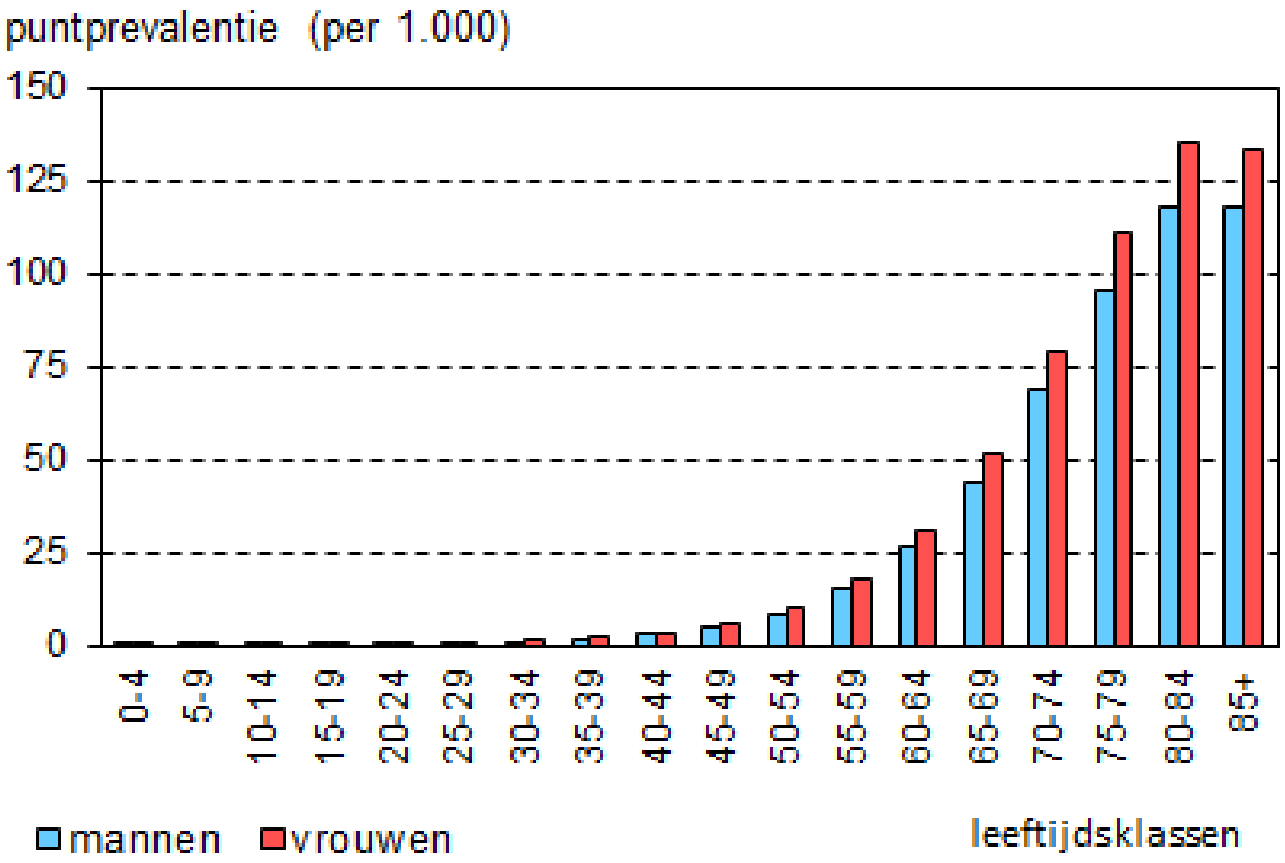
Visual impairments in the Netherlands
(RIVM, 2011)



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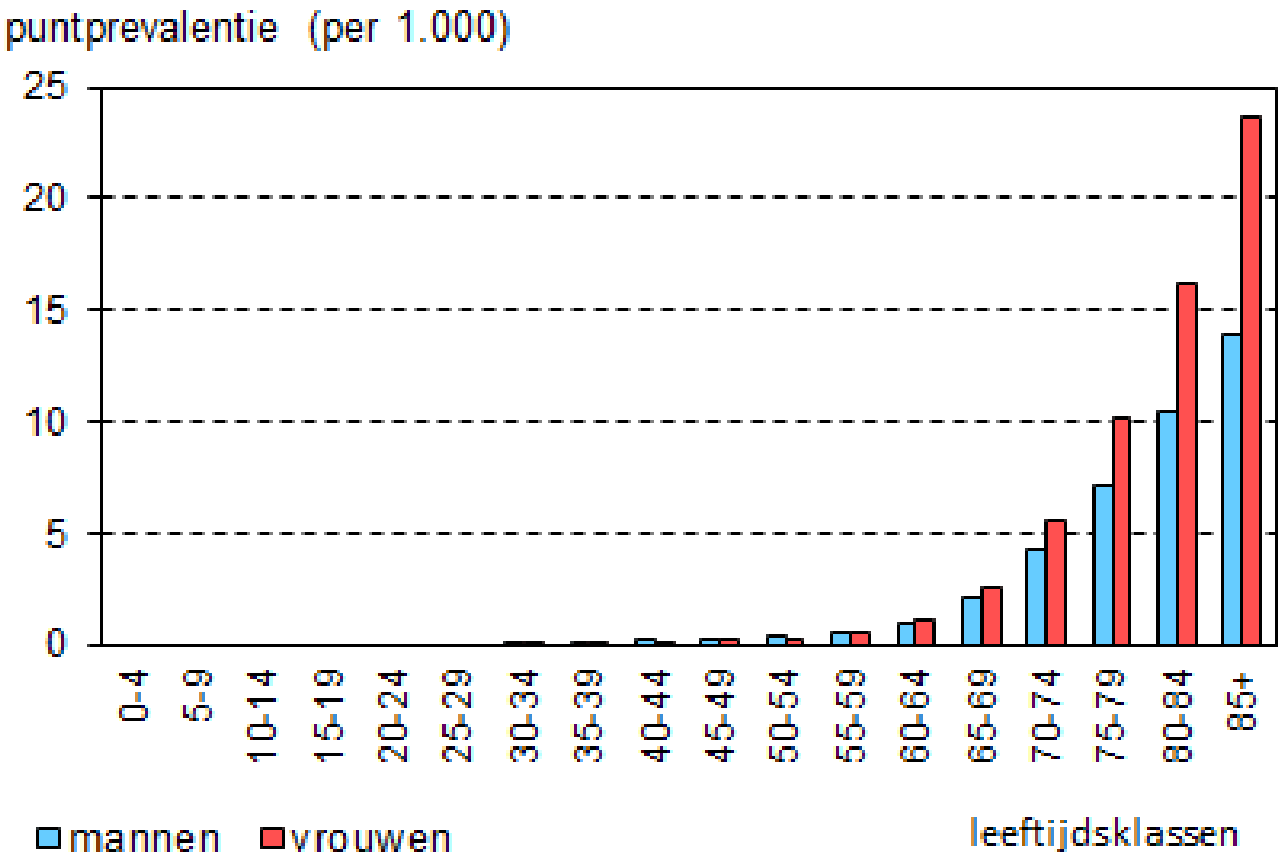
Macula Degeneration



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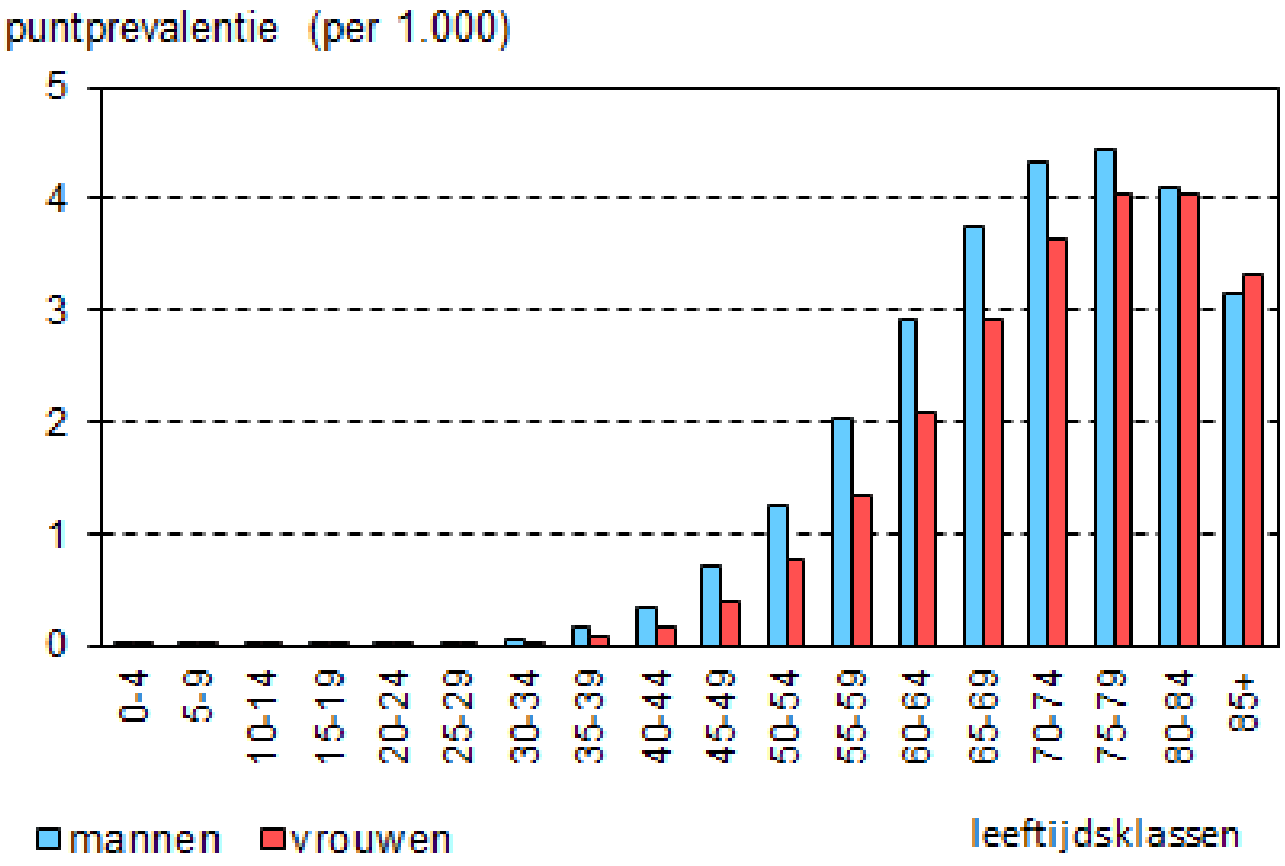
Diabetic Retinopathy



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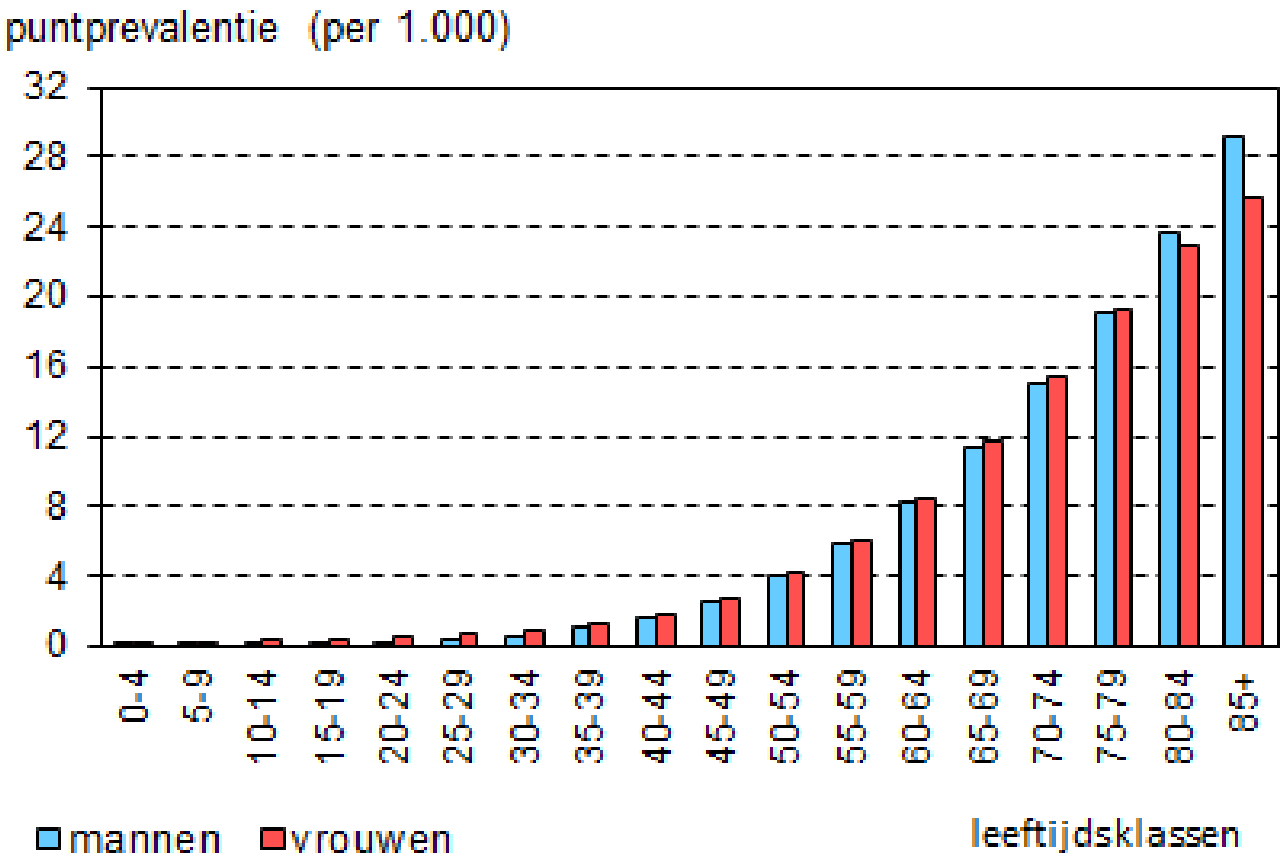
Glaucoma



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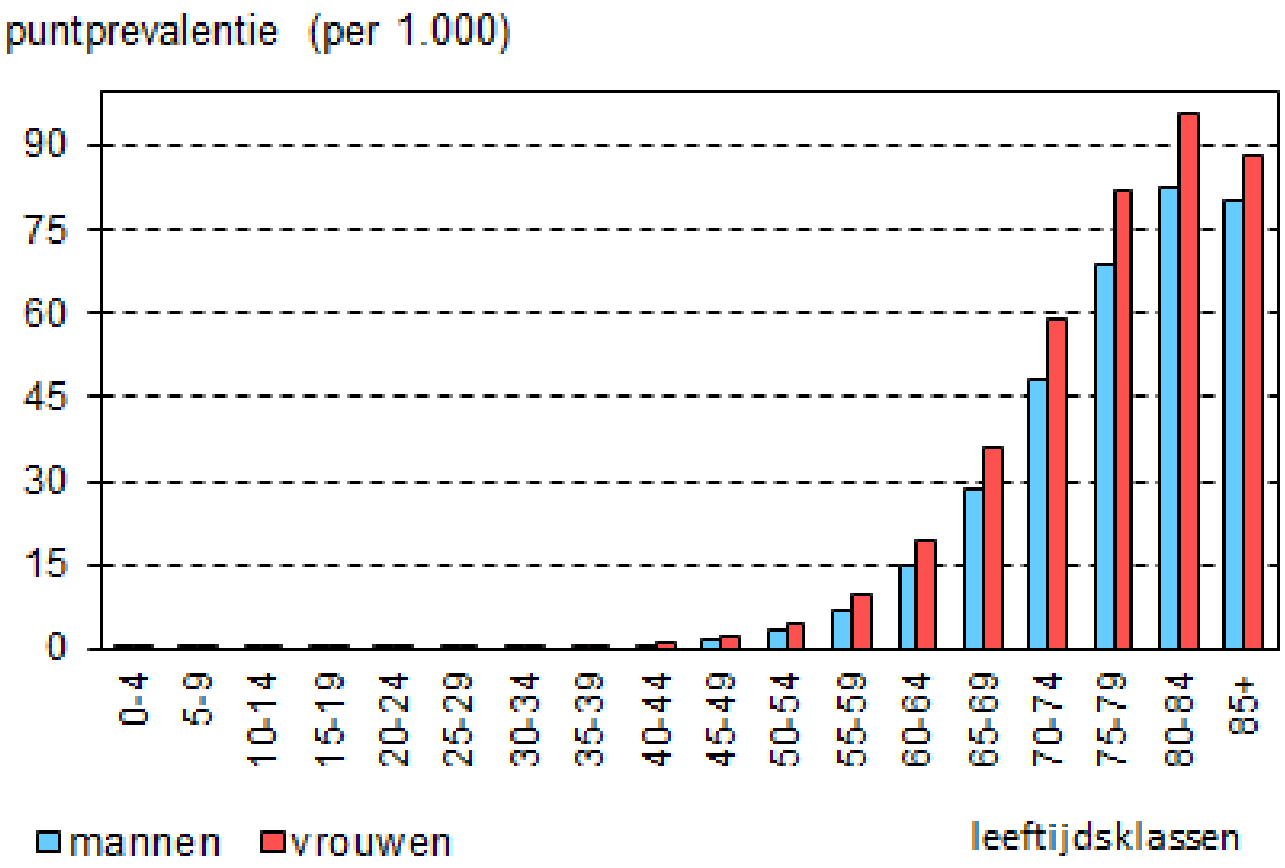
Cataract



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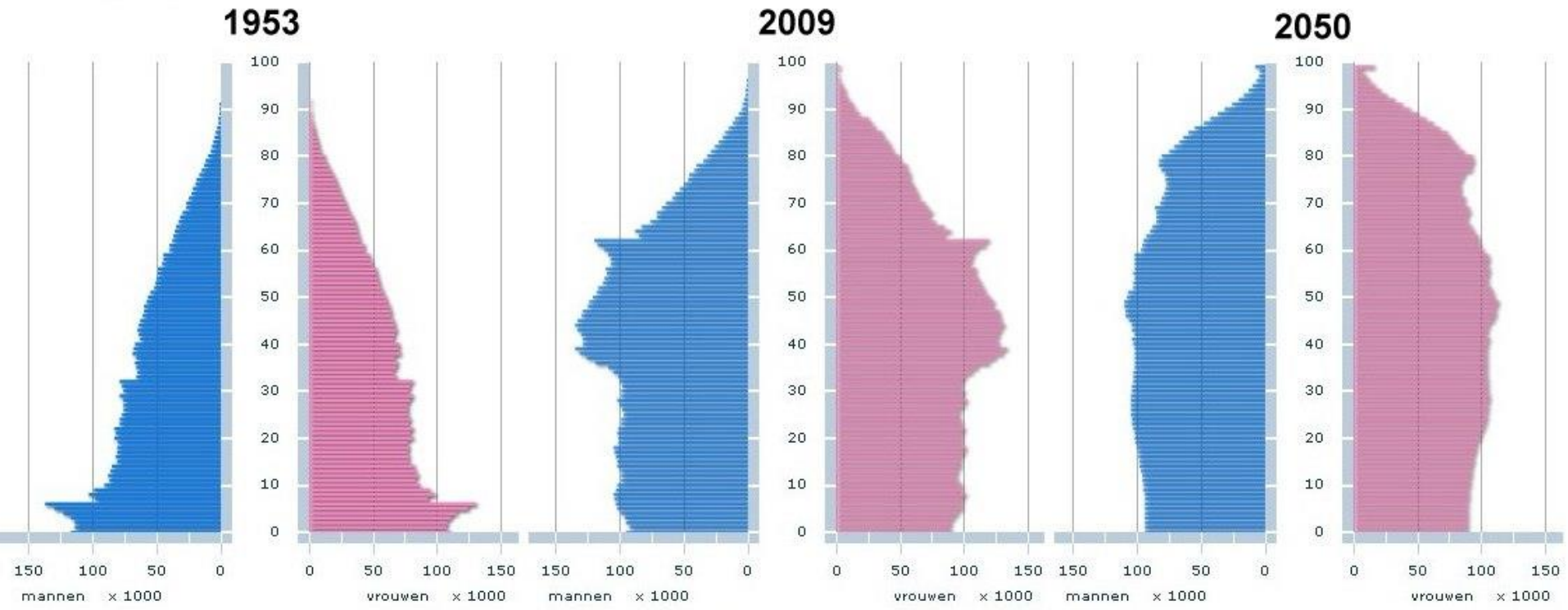
Population pyramid the Netherlands



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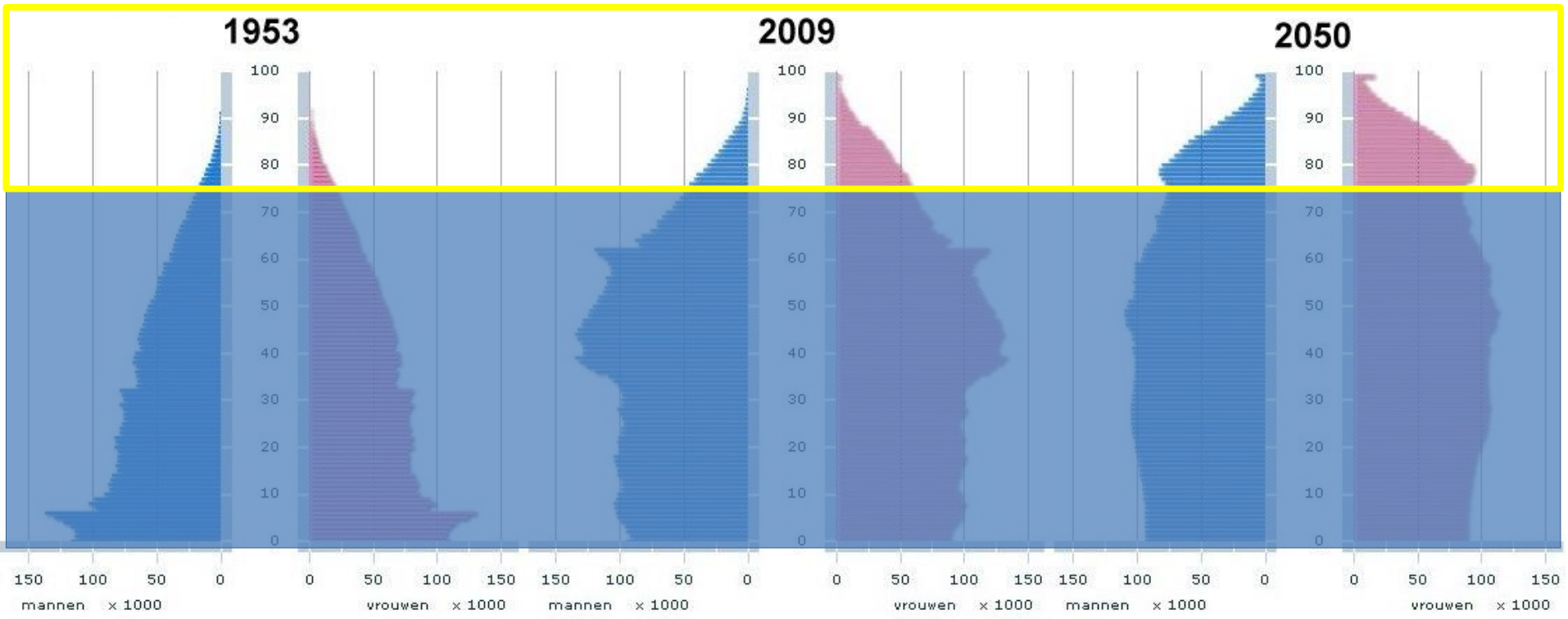
Population pyramid the Netherlands



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VIVIS 2020 session

- 3 Dutch VI service providers:
  - Royal Dutch Visio
  - Bartiméus
  - Robert Coppes Foundation

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VIVIS 2020 session; subjective selection of expectations for the future (1)

- Because of the interdependency of hearing and seeing it is to be expected that we need to cooperate more closely with the field of hearing loss.
- It is to be expected that the number of VI older people will grow. However new medical developments may lead to a declining number, so maybe there will not be that many changes.

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VIVIS 2020 session; subjective selection of expectations for the future (2)

- As a result of more societal participation and less residential facilities the severity of concern in these residential facilities will increase.
- Also because of increasing technical possibilities regular service providers will consult the VI specialised service providers more often.
- This will lead to more out-reaching services and sharing of knowledge and expertise.

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VIVIS 2020 session; subjective selection of expectations for the future (3)

- Increasing technical possibilities will urge the VI service providers to become specialists in using and implementing technology in care and rehabilitation. Also with regard to VI older people.
- VI service providers need to develop into centres of expertise and will need to share that expertise with other service providers.

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Specific training courses needed on VI and ageing in addition to existing curriculum

- Symptoms / recognition of common eye diseases at old age
- Practical adaptations (lighting, magnification, contrasting colours)
- Communication skills (of the professionals)
- Daily living skills
- Safe mobility in and around the house
- Low vision assessment / Light perception and adaptations
- Emotional consequences of vision loss (including depression)
- Dual sensory loss at old age
- Ageing and the brain (including dementia, stroke, Charles Bonnet syndrome, sleep disorders)

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Research programme InZicht (InSight)

- From 2001 till 2015: 69 research projects
- 18 including VI older people
- 12 explicitly aimed at VI older people

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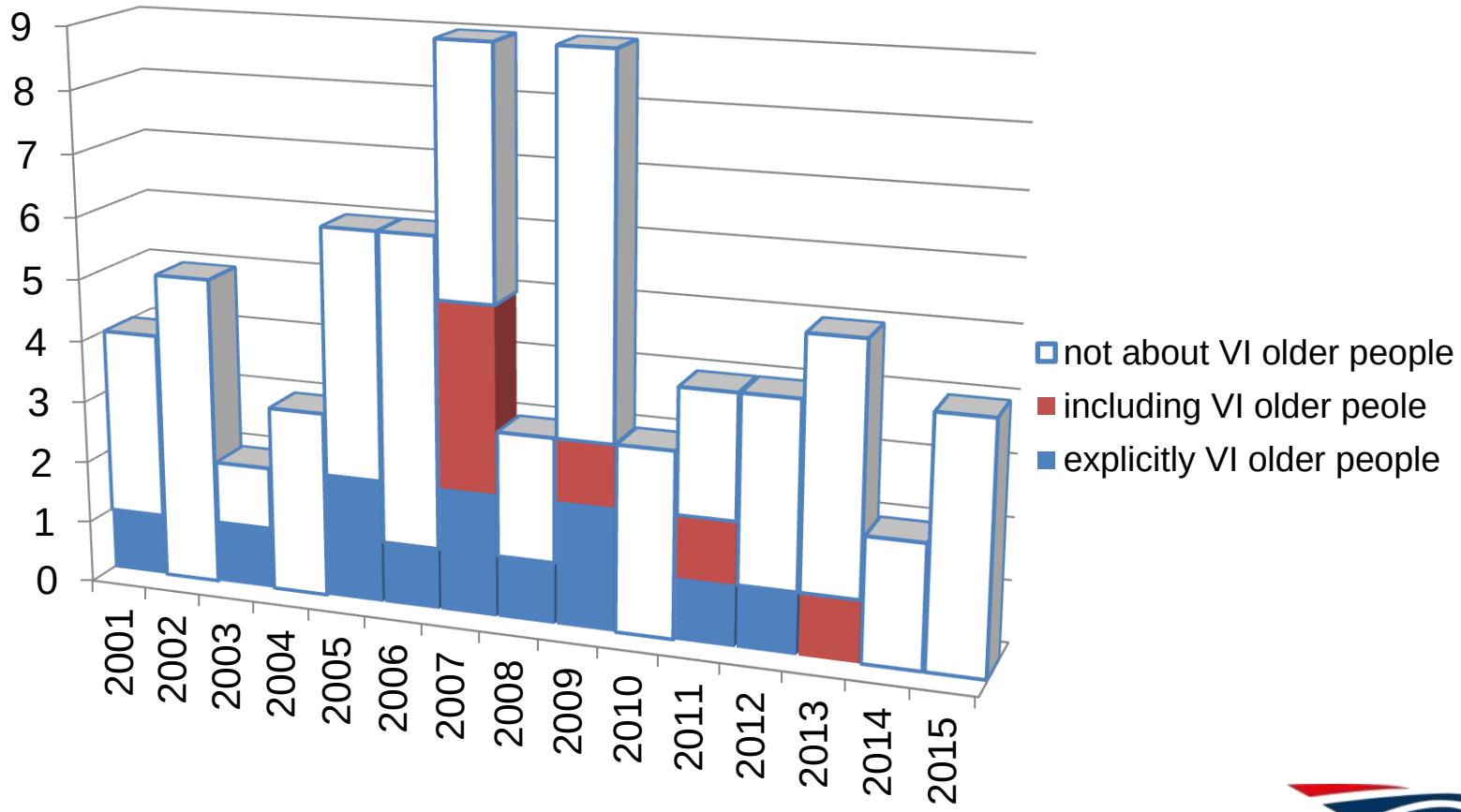
Number of InZicht projects started per year



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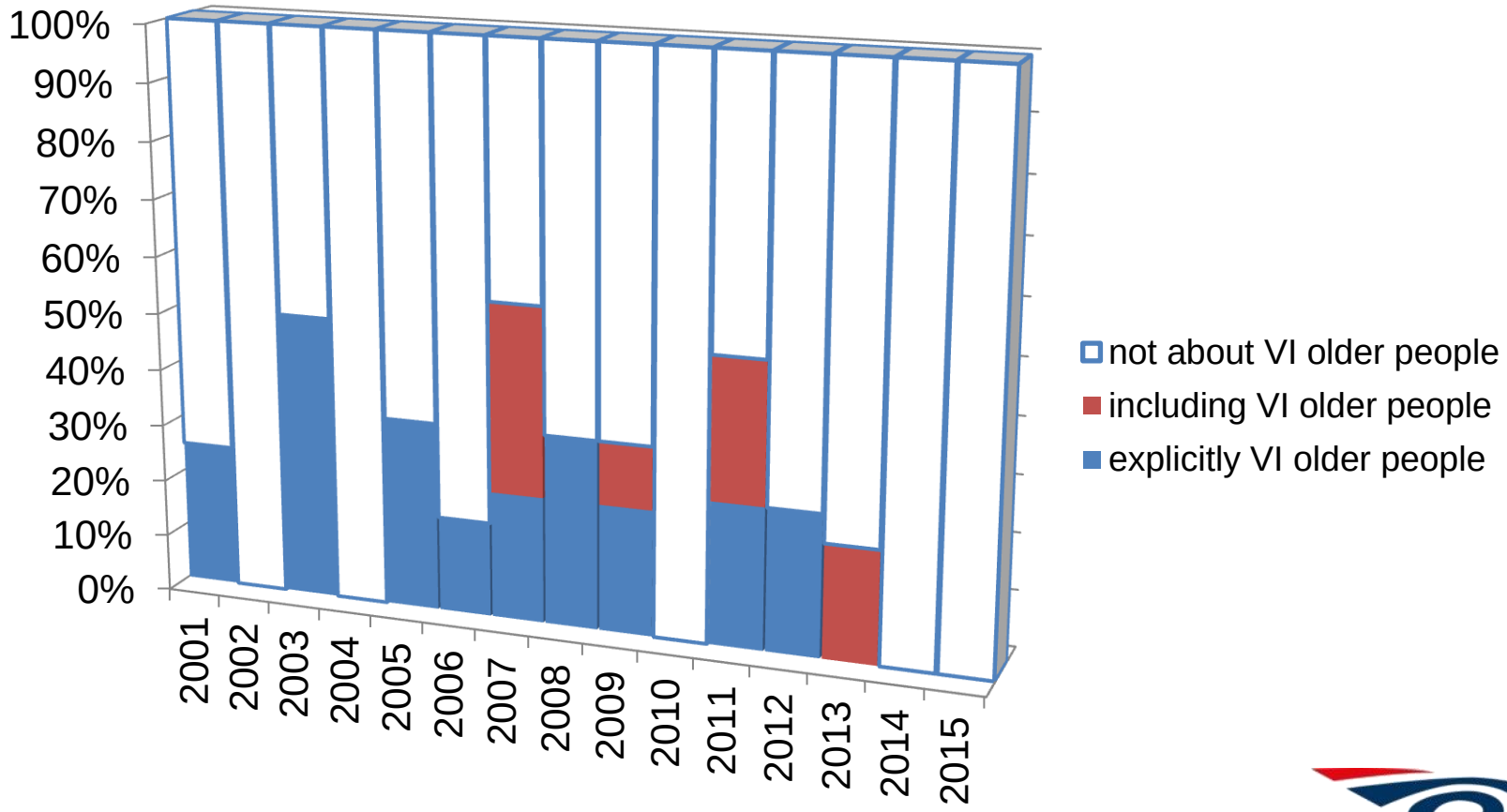
Percentage of InZicht projects started per target group per year



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Research challenges

- Continuous attention for the largest target group
- Complexity because of multimorbidity
- Focus on evidence based interventions
- Focus on effectiveness of outreaching care
- Focus on effectiveness of cooperation in the care chain
- Cooperation in research consortia with other partner organisations
- Technological innovations

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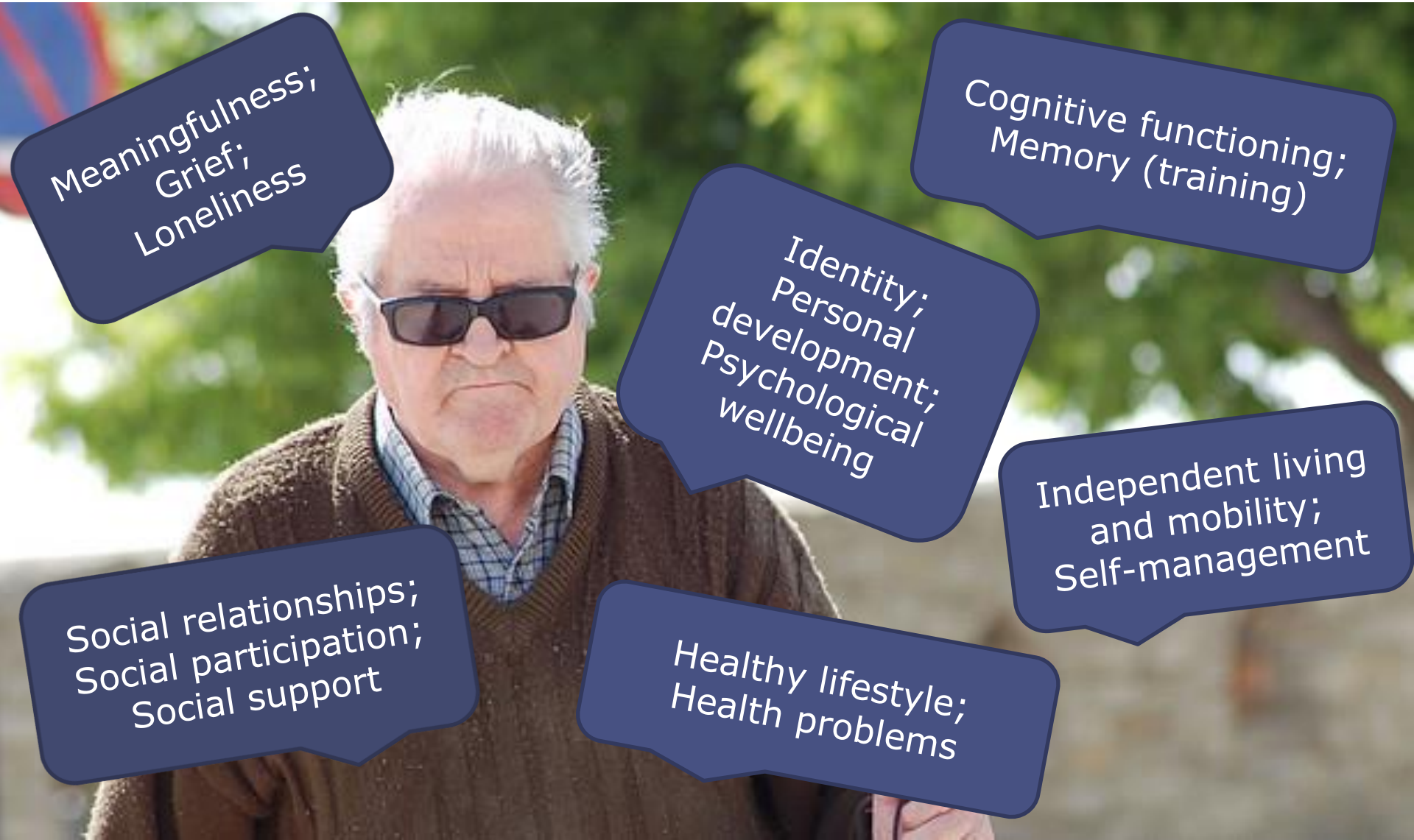
Many themes on VI and ageing



European perspective

- 850 million people
- 54 countries
- 15 time zones
- 19 of the world's 20 oldest countries

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% older people in total population

Region	Year	≥ 65	≥ 80
Asia	2000	5.9	0.9
	2030	12.0	2.3
Europe	2000	14.7	3.0
	2030	23.5	6.4
Latin America / Caribbean	2000	5.6	1.0
	2030	11.5	2.5
Middle East / North Africa	2000	4.4	0.6
	2030	8.4	1.4
North America	2000	12.4	3.3
	2030	20.0	5.4
Oceania	2000	10.1	2.3
	2030	16.3	4.4
Sub-Saharan Africa	2000	2.9	0.3
	2030	3.6	0.5

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% of older people in total population

Year	Eastern Europe		Western Europe	
	≥ 65	≥ 80	≥ 65	≥ 80
2010	14.4	3.4	18.2	5.2
2020	18.6	4.5	20.9	6.2
2030	22.2	5.8	24.7	7.5
2040	25.6	8.4	28.0	9.3
2050	30.3	9.6	28.6	11.4

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Prevalence of visual impairment

- Prevalence of visual impairment in Europe is 1.75% of total population
- 15.5 million people in Europe are visually impaired
- 79% of all visually impaired people in the Netherlands are 65 years of age or older
- About 12 million visually impaired older people in Europe

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European projects EBU

- Intergen
- Low Vision
- Rehabilitation of VI older people
- VISAL

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Intergen

- Workshops where young participants shared their skills with senior peers: mobile phones, tablets, emailing and specific accessible technologies.
- In turn, senior participants passed on their skills by teaching younger people how to perform essential daily tasks such as cooking, ironing or gardening.
- Innovative workshop guidelines to encourage others to organise their own intergenerational projects.

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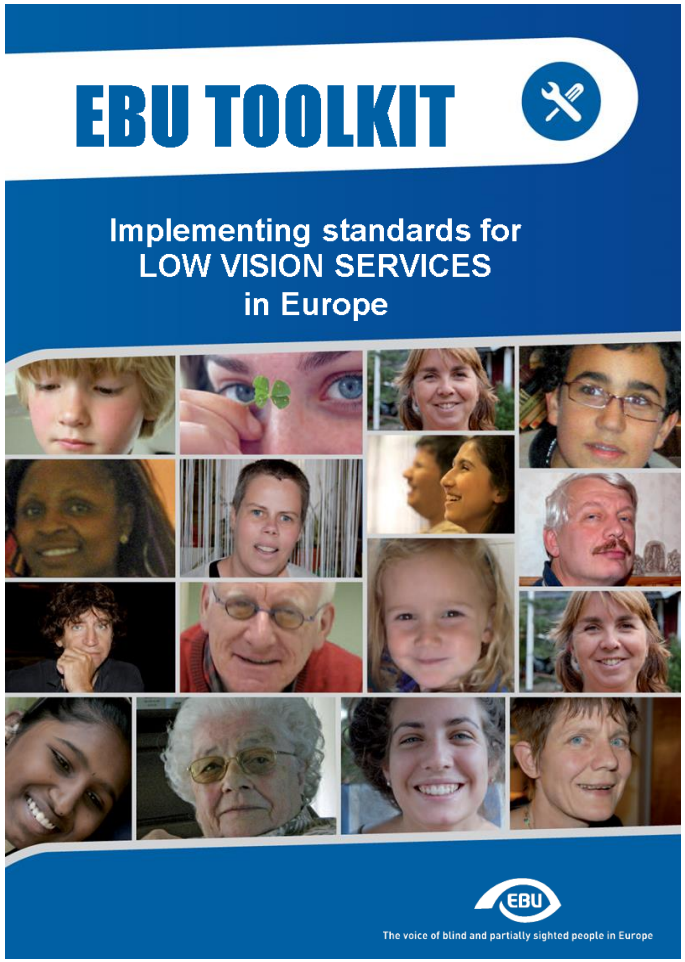
Low Vision



A toolkit with examples and references which will be useful when undertaking action nationally to promote and lobby for high level low vision services to be made available and accessible to everyone with sight loss in need of support

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Rehabilitation of VI older people

- Position paper on Rehabilitation of older people with acquired sight loss
  - Alan Suttie (†)
  - Elaine Howley
  - Gordon Dryden
  - Huld Magnúsdóttir
  - Peter Verstraten
  - in cooperation with: Geert Joosten and Niall McMurtry

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Recommendations EBU on rehabilitation of older people with sight loss

- Older people with sight loss need to be included in the making of ‘their’ rehabilitation model and what it means to them, as traditional rehabilitation models are created by younger people for young people.

- How?
- What?
- Where?

} rehabilitation offered?

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Recommendations EBU on rehabilitation of older people with sight loss

- Marketing and awareness in society and amongst professionals and ophthalmologists as main referrers
- Because of comorbidity, VI rehabilitation services should be part of a care chain of service provisions
- Involvement of:
  - Partner and family
  - Peer support
  - Intergenerational services
  - Volunteers and informal care givers
- Tele-rehab and welfare technology become more important
- Staff training in working with older people is needed
- Awareness of the risk of over-emphasis on formal assessments

How

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Recommendations EBU on rehabilitation of older people with sight loss

- There needs to be a clear focus on daily practice
- With concrete goals based on individual requests/priorities
- Low vision assessment and training
- Use of technology
- Dealing with loss at old age
- Memory training
- Physical exercise, to improve strength and balance

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Recommendations EBU on rehabilitation of older people with sight loss

- The starting point is that rehabilitation services should be offered on a centre basis, because of
  - Interdisciplinary working
  - Comorbidity
  - Group work

  However accessibility, transport and dependency are issues to be taken care of.

- Home based follow-up is sometimes necessary.
- Informal and social contacts are often needed.

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VISAL

Visually Impaired Seniors Active Learning

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VISAL: Aims

- Develop a VISAL guide formalising European non-formal learning good practice for older VI persons,
- Hold VISAL workshops with older VI participants to train them and remain them active in society,
- Exploit the skills acquired during the VISAL workshops by encouraging older VI participants, to hold an event together with older persons without visual impairment,
- Promote dialogue, experience exchange and active collaboration between older VI persons and able-bodied older persons,
- Place the issue of the engagement of older VI persons high on national VI organisations' agenda.

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VISAL: Objectives

- Increase skills and competences of older VI persons,
- Enhance attractiveness of and access to adult learning for older VI persons and boost their motivation to further train themselves,
- Value the experience of older VI persons,
- Increase participation and representation of older VI persons in civil society (and in national EBU member organisations),
- Fight against isolation of older VI persons,
- Allow for a higher integration of older VI persons' concerns in the design of disability and non disability policies and strategies.

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VISAL: Partners

- The consortium that developed VISAL comprises 7 partners:

- European Blind Union (EBU)
- Age UK (UK)
- Austrian Federation of the Blind and Partially Sighted (BSVÖ, Austria)
- Slovak Blind and Partially Sighted Union (UNSS, Slovakia)
- Croatian Association of the Blind (HSS, Croatia)
- Royal National Institute of Blind people (RNIB, UK)
- Royal Dutch Visio (Visio, the Netherlands)

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VISAL: Methodology

- Experts from VI organisations developed the VISAL guide together.
- Their experienced experts have trained facilitators
- These facilitators are responsible for leading VISAL workshops with older VI learners in their own countries.
- Older VI participants collaborated with older persons without VI and organised a national conference on lifelong learning for elderly VI persons.

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VISAL: Evaluation (Dominique Danau; 2014)

- Improvement in:
  - Self-esteem
  - Confidence
  - Mental well-being
  - Civic engagement

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VISAL: Impact

- VISAL programme is about empowerment and participation.
- Not only about the toolkit or sessions, but about the message how to involve VI older people in a meaningful and respectful way in society and that it works.
- Influencing the local habitat through informal learning opportunities, through involvement and engagement.

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VISAL: Continuation

- Participation Award in Austria
- The VISAL toolkit is available in Croatian, Dutch, English, French, German, Italian, Norwegian, Slovak and Spanish
- The course was experimented in Austria, Croatia, Slovakia and the UK, and has later been implemented in France, Hungary, Italy, Lithuania, the Netherlands, Portugal, Poland and Greece.

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VISAL: Continuation

http://www.visal-project.eu/

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European project ENVITER

- SensAge: European Network on Lifelong Learning Needs for Ageing People with Sensory Disabilities
- http://www.sensage.eu/knowledge-base

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Knowledge base on ageing and vision loss and/or hearing loss

Research ICEVI + EBU + VU Amsterdam

- Rosaline de Korte: Services for Visually Impaired Elderly Persons in Europe (2015)

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What services are provided for VI older people in Europe?

- Six service categories were selected: psychosocial support, reading, orientation and mobility, domestic life, communication and leisure
- AAA-framework: availability, accessibility and affordability

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Results (1)

- Leisure activities (80%) and psychosocial support (79%) were most often available
- The availability of the service categories is almost equal to their reported accessibility
- All European countries provide at least one or two types of services for VI older people
- Government is the most important financer for all service categories

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Results (2)

- All service categories are generally covered available and accessible for VI older people
- Additionally, the majority of countries indicated that at least some types of services were provided in all service categories
- Additional studies will be needed. Questionnaire was sent to 44 national member countries of the EBU. 20 replied.

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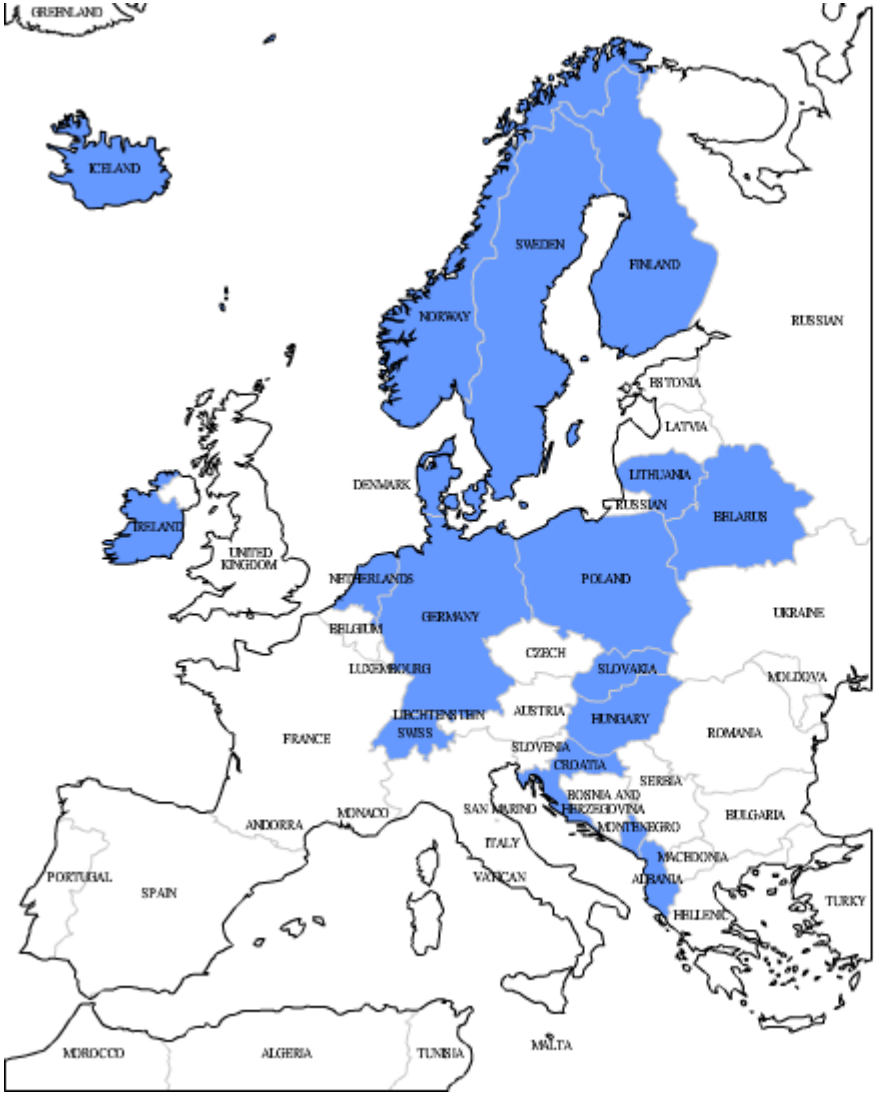
Countries that participated in survey



Numbers of Visual impaired adults > 50 years, both male and females, 2010. Retrieved from the Global Vision Database Maps, IAPB.

	Population affected	Prevalence
- Albania	60.992	7.8%
- Belarus	184.573	5.3%
- Croatia	145.832	7.5%
- Cyprus	310.613	3.5%
- Denmark	66.131	2.7%
- Finland	82.163	3.3%
- Germany	1.401.576	3.3%
- Hungary	299.036	7.0%
- Iceland	2.934	2.7%
- Ireland	49.603	3.5%
- Kazakhstan	151.010	5.0%
- Lithuania	76.958	5.7%
- Malta	5.751	3.6%
- Montenegro	15.299	7.4%
- Norway	56.833	2.8%
- Poland	956.894	6.6%
- Slovakia	114.053	6.4%
- Sweden	142.774	3.1%
- Switzerland	106.695	3.1%
- The Netherlands	172.164	2.5%

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Global perspective

- The world is getting older
- The number of VI older people will increase
- WBU calls for an action plan to reduce the impact or burden of sight loss, achieved through the delivery of improved support

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Growth of older people in Africa

Country	2010		2020		2030		2040		2050	
	≥ 65	≥ 80	≥ 65	≥ 80	≥ 65	≥ 80	≥ 65	≥ 80	≥ 65	≥ 80
Angola	2.7	0.2	2.5	0.1	2.8	0.1	3.1	0.1	3.7	0.1
Botswana	3.9	0.4	4.3	0.5	5.6	0.7	6.5	1.0	8.7	1.3
Burkina Faso	2.5	0.1	2.4	0.1	2.6	0.1	3.3	0.1	4.1	0.2
Cen Af Rep	3.8	0.1	3.4	0.2	3.7	0.2	4.4	0.2	5.3	0.3
Egypt	4.4	0.1	6.0	0.3	8.0	0.5	9.5	0.9	13.1	1.4
Ethiopia	2.7	0.1	2.7	0.1	2.8	0.1	3.1	0.2	3.8	0.2
Nigeria	3.1	0.1	3.4	0.1	3.9	0.1	4.8	0.2	6.2	0.3
Sierra Leone	3.6	0.1	3.7	0.1	3.6	0.2	4.5	0.2	6.2	0.3
South Africa	5.5	0.3	7.4	0.5	9.2	0.8	9.9	1.3	11.4	1.8
Tanzania	2.9	0.1	3.3	0.1	3.8	0.2	5.0	0.3	7.1	0.4

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Action plan (1-5)

- Identify and understand the incidence, impact and needs
- Need for Greater Education and Awareness
- Early Intervention
- Establishment of Low Vision Support Groups
- Provision of low cost Assistive Technology, Aids and Training

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Action plan (6-10)

- Isolation interventions
- The Role of Government & Business
- Removal of the Barriers to Transport and Physical Access
- Advocacy/Citizenship
- Best Practice and Partnerships

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International Consensus Conference
December 2015

WHO:

International Standards for Vision Rehabilitation
(2017)

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Strengths of VI Rehabilitation in Europe

- Wide range of professional experience
- Strong institutions in some leading countries
- Networks well developed in certain regions
- Private sector and NGO’s are active
- Associations of patients are strong

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Weaknesses of VI Rehabilitation in Europe

- Categorisation and definitions are not harmonised
- Expertise, references and guidelines are not standardised
- Assessment is lacking
- Insufficient coordination
- Training of personnel is inadequate
- Lack of government acknowledgment

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Opportunities for VI Rehabilitation in Europe

- New treatments are becoming available for blinding diseases
- Post-treatment rehabilitation can be further developed

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Threats to VI Rehabilitation in Europe

- Economic crisis has put pressure on funding
- Transport issues can cause barriers to access

SWOT analysis by

Prof. Pierre-Yves Robert

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Standards for VI rehabilitation (1)

- Approach should be multidisciplinary and person-centred
- Based on individual goals and risks
- Collaboration, cooperation and communication between professionals at different levels
- Data collection from primary level
- In children as early as possible

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Standards for VI rehabilitation (2)

- New definition of VI includes troubles with visual cognition
- Vision rehabilitation instead of visual rehabilitation
- Competencies rather in terms of skills than professional roles
- Necessary to develop curricula for workers in vision rehabilitation

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Standards for VI rehabilitation (3)

- Multidisciplinary approach coordinated by rehabilitation supervisor
- Make use of WHO-TARSS (tool for assessment of rehabilitation and support services) to assess rehabilitation needs and gaps in service provision

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Vision 2020: The right to sight

- An estimated 45 million people worldwide are blind.
- Every year, an additional 1-2 million persons go blind.
- More than two-thirds of this blindness is treatable and preventable.
- A majority of the blind live in the poorest section of the developing world.
- Without proper interventions the number of blind will increase to 75 million by 2020.
- Restoration of sight is one of the most cost-effective interventions in health care.

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Conclusions

- Share best practices
- Develop new knowledge as forerunners in ageing
- Cooperation
- In dialogue with the target group!

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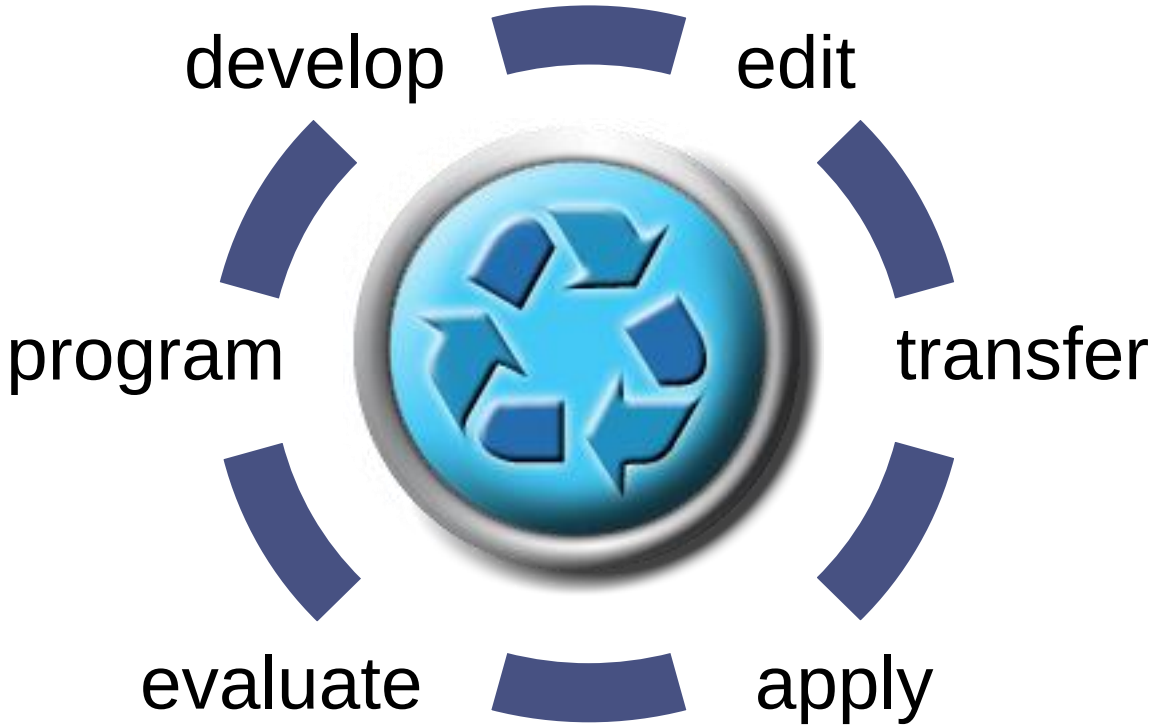
Knowledge circle



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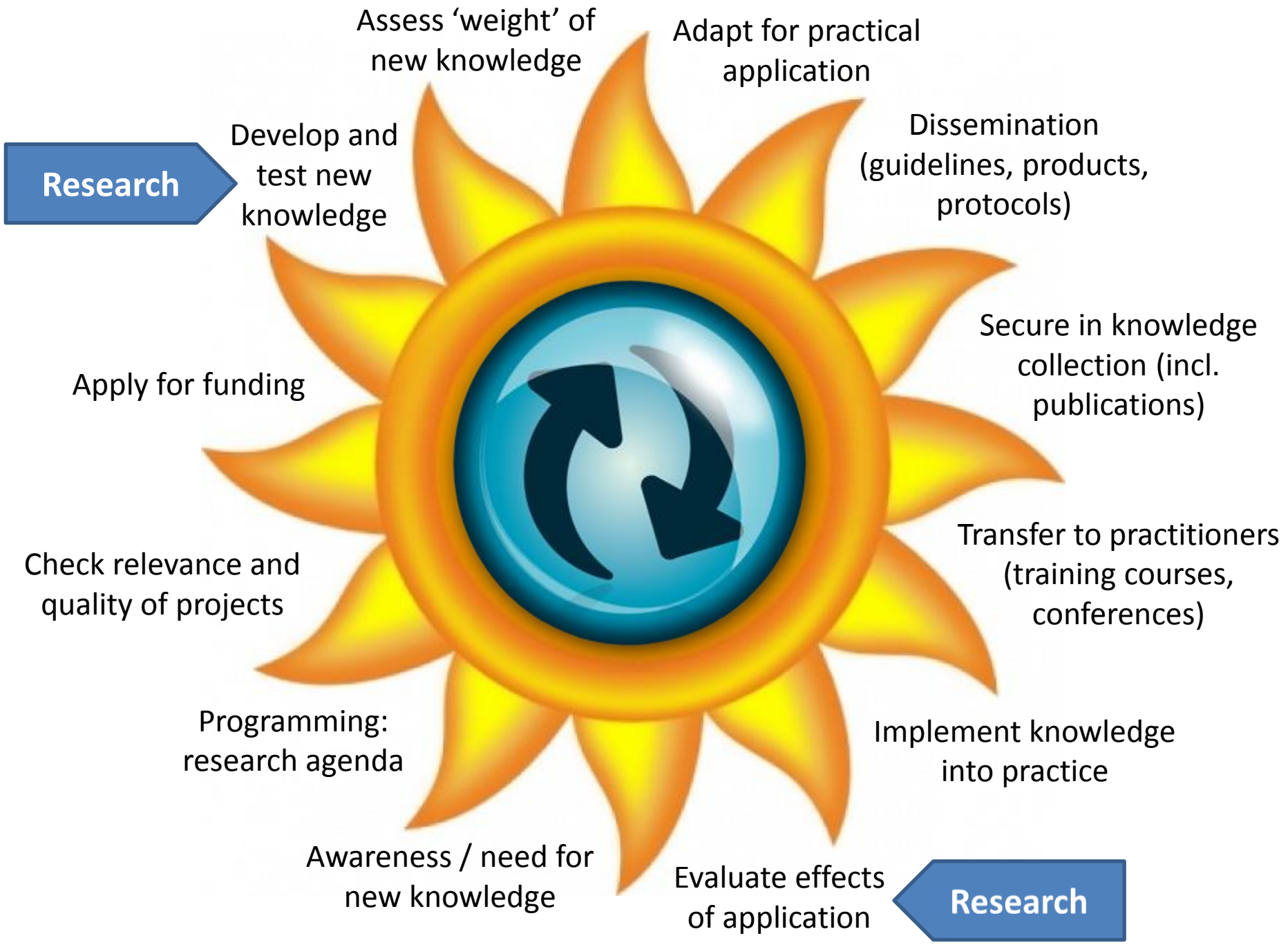
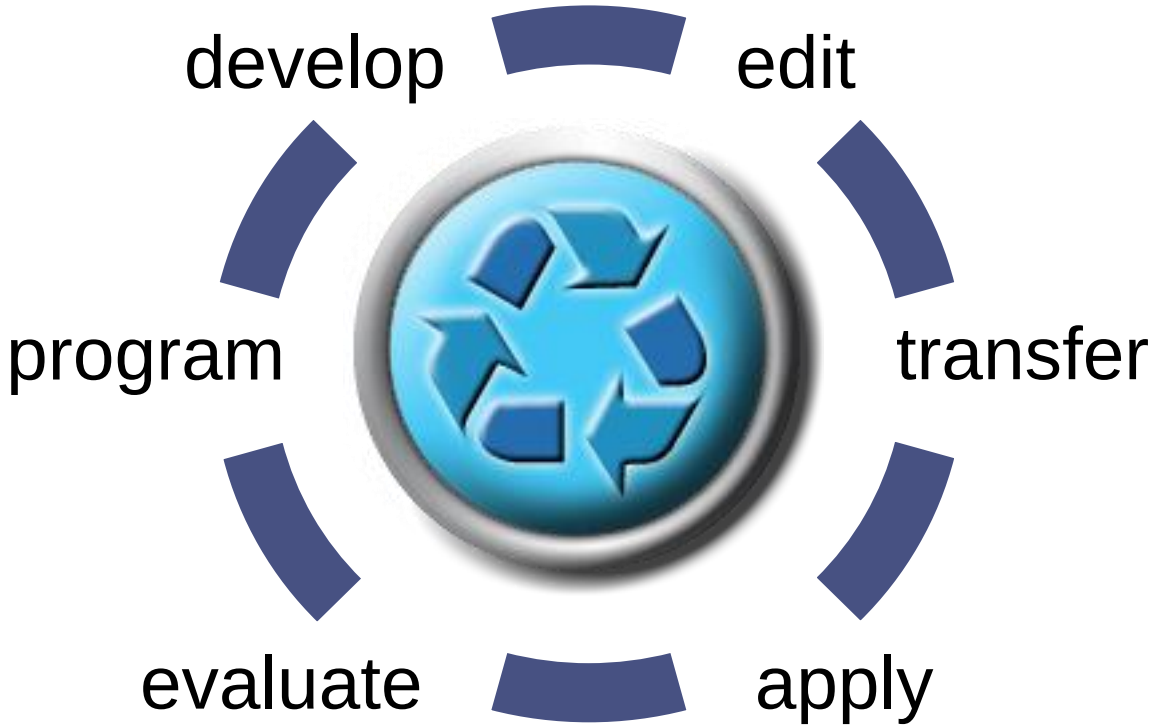

Assess 'weight' of new knowledge
Adapt for practical application
Research
Develop and test new knowledge
Dissemination (guidelines, products, protocols)
Secure in knowledge collection (incl. publications)
Apply for funding
Transfer to practitioners (training courses, conferences)
Check relevance and quality of projects
Programming: research agenda
Implement knowledge into practice
Awareness / need for new knowledge
Evaluate effects of application
Research

Knowledge circle: with the target group!



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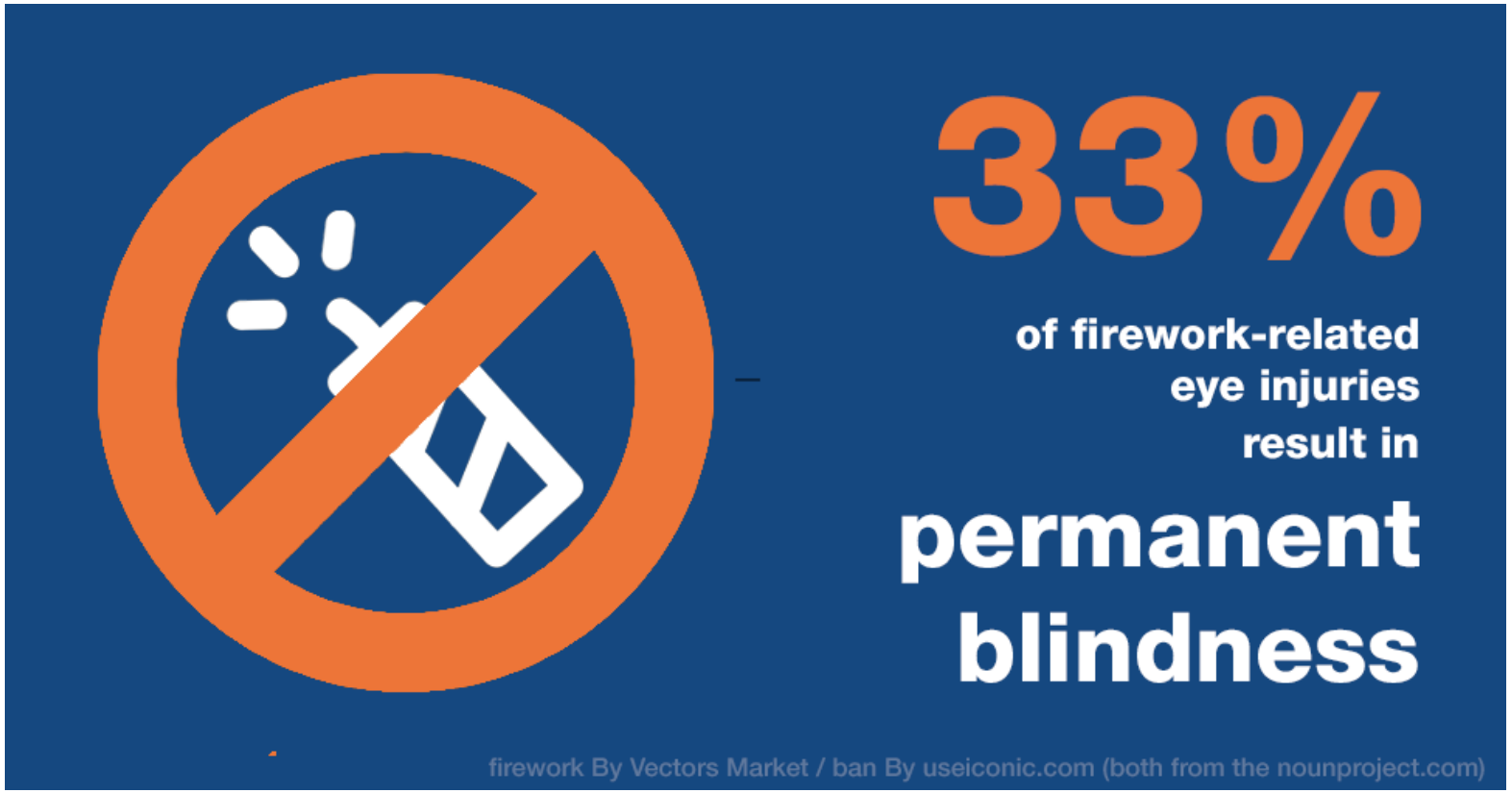
Prevention is better than cure



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Prevention is better than cure

- 50% of all visual impairment in the developed countries is caused by Macular Degeneration
- Smoking is the largest modifiable risk factor for age-related macular degeneration
- So …

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