

Welcome to my reality

a patient's tale of innovation

Bart Scheenaerts MBA

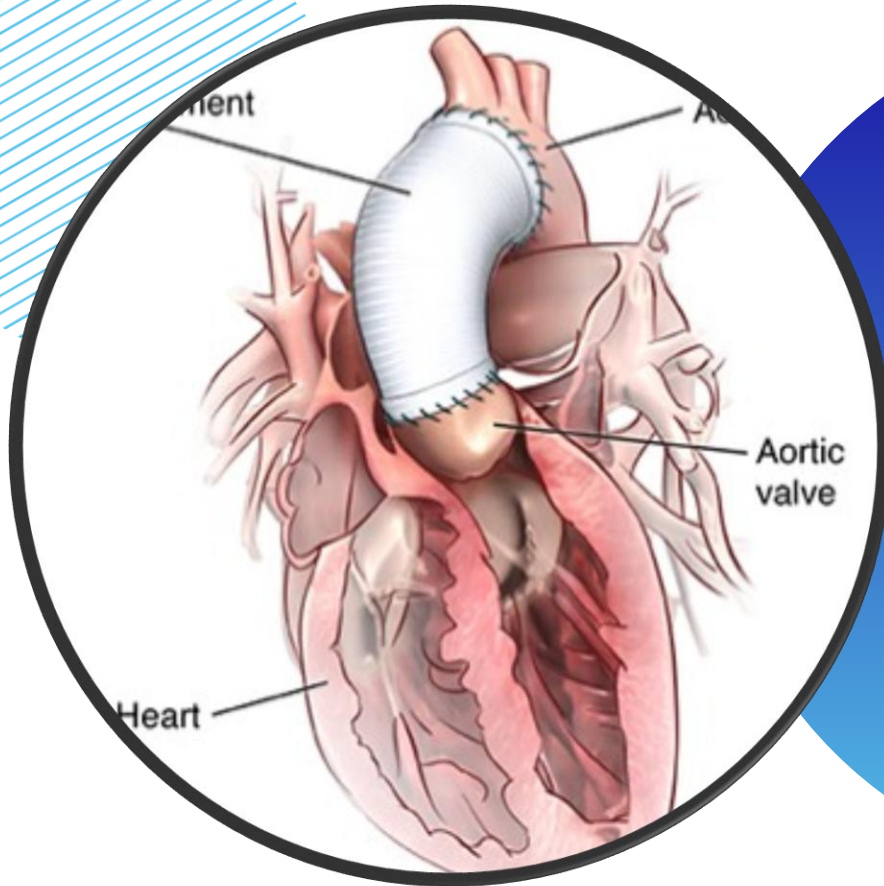
Patient advocate
& Independent digital innovation consultant

Patient Forum Member
ESC | European Society of Cardiology



15 – 08 – 2020





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**Dialed 112
excrutiating pain
on the right side
of my back**

Aorta dissection

Difficult diagnosis

**Seen 1st cardiologist in my
life on emergency**

30 hours in ER before surgery

Good guardian angel

16 – 08 – 2020







2x - 08 - 2020









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Half-blind, Sir.

No improvement
possible.
Sorry....

Cardiovascular surgery

15 hours

Ischemic stroke

during the procedure

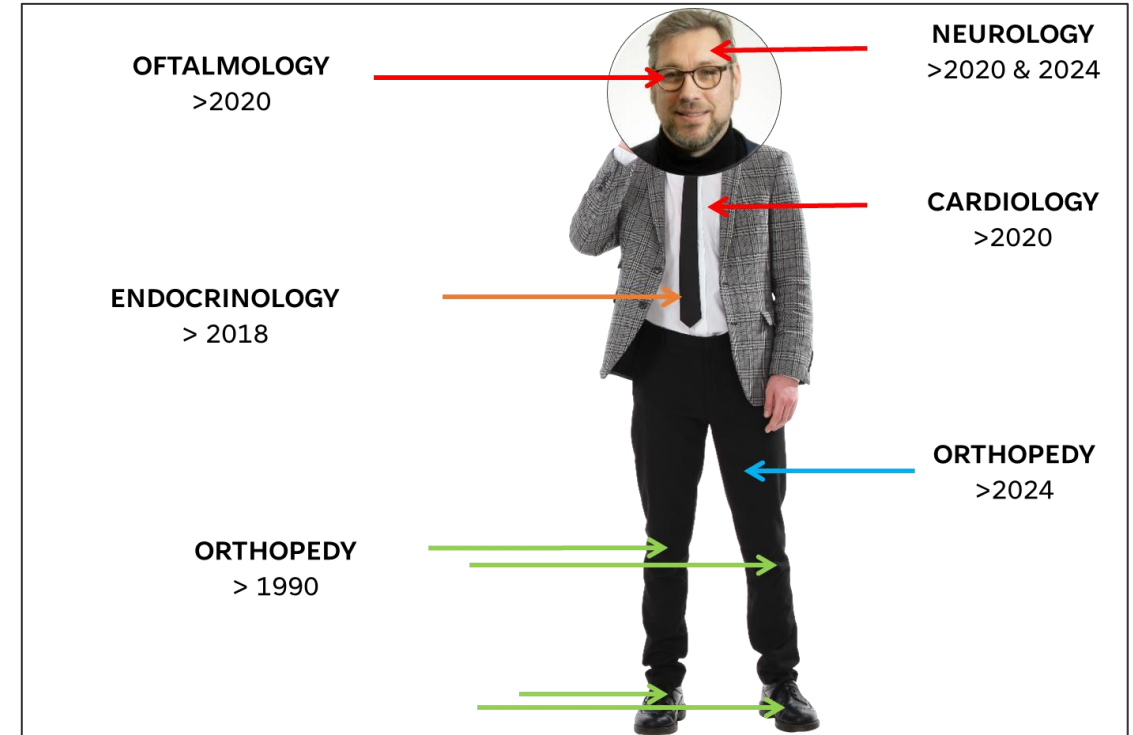
Result: I'm still alive

What ? Really ?

Consequence: RHH

Right Homonymous
Hemianopia (Low Vision)

Multidisciplinary Revalidation



Revalidation in the hospital

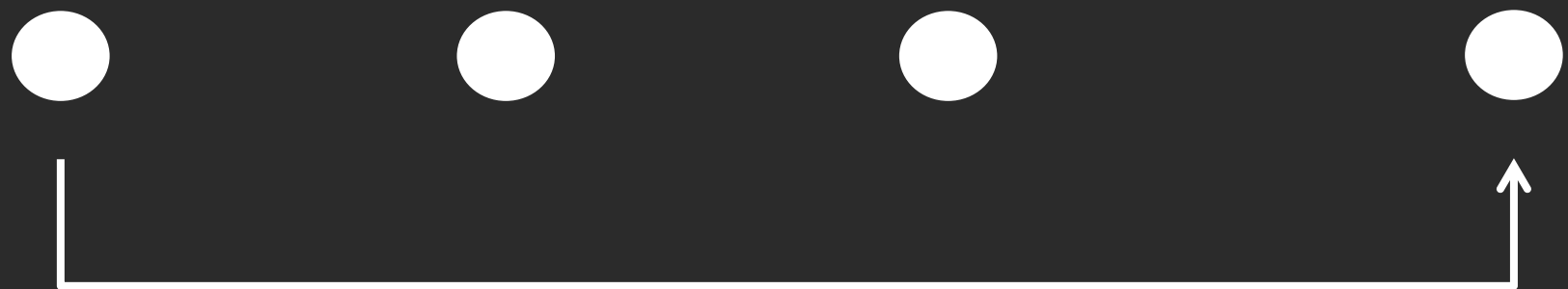
Learn to stand | walk | move | see again

Q3-Q4 / 2020





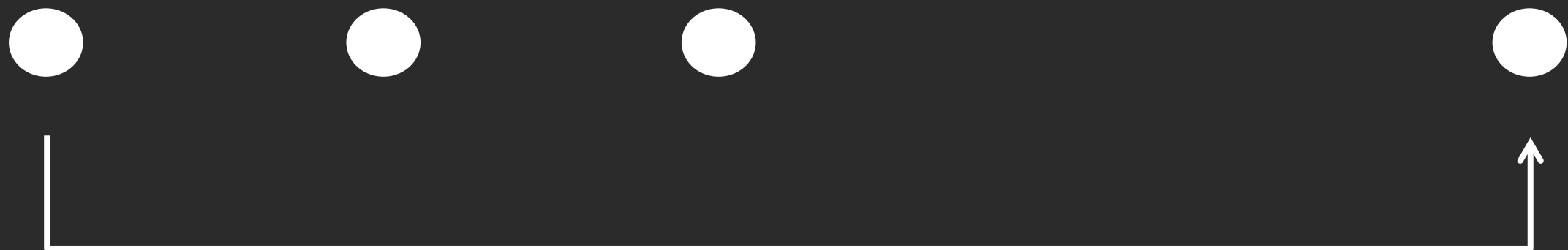












Results of in-hospital revalidation

- **Primary revalidation:** new vision strategy to cope with the new situation
- Follow-up in **specialized centre**, to learn:
 - walking in crowded places,
 - using a cane
 - driving a bike (and yes, a car)
- **But: no regain of vision field**



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**2021: back to work
on the look for
innovation**

My profession

Program manager
Digital innovation
Public & private sector

My belief

If it's not possible now, we
need **research & innovation**

My commitment

If not for me, I'll contribute
for **next generations**

Taking part in scientific research (2021-22)



SCAN ME

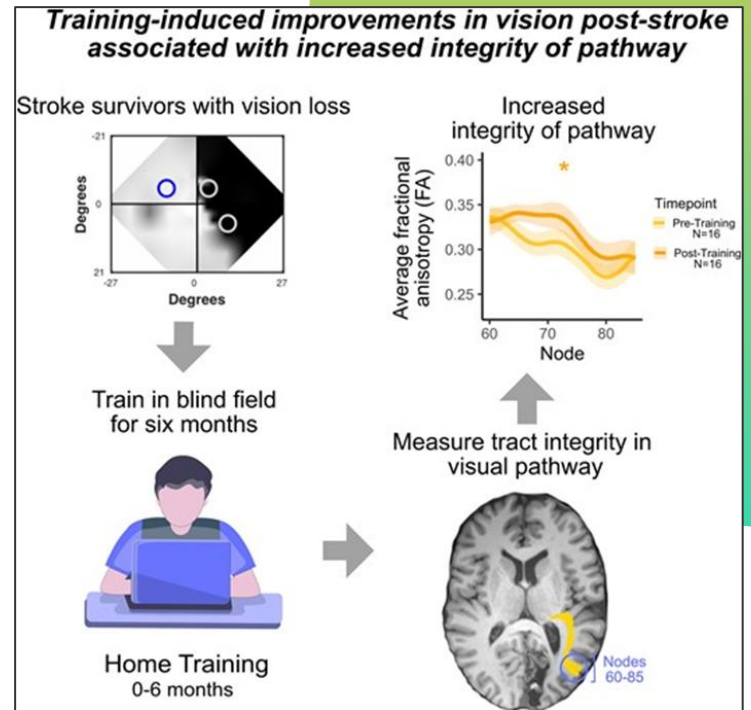
<https://doi.org/10.1093/braincomms/fcae323>

BRAIN COMMUNICATIONS 2024: fcae323 | 1

BRAIN COMMUNICATIONS

Rehabilitating homonymous visual field deficits: white matter markers of recovery—stage 2 registered report

Hanna E. Willis,¹ Bradley Caron,² Matthew R. Cavanaugh,³ Lucy Starling,¹ Sara Ajina,⁴ Franco Pestilli,⁵ Marco Tamietto,^{6,7} Krystel R. Huxlin,³ Kate E. Watkins⁸ and Holly Bridge¹





My quest for innovation with half a vision field

TO REGAIN A PART OF MY LOST VISION FIELD

Hybrid scientific research program: in Oxford (Nuffield institute) and at home in Antwerp, Belgium

1

Travel to Oxford



2

Oxford MRI & tests



3

Rochester NYC
Software configuration

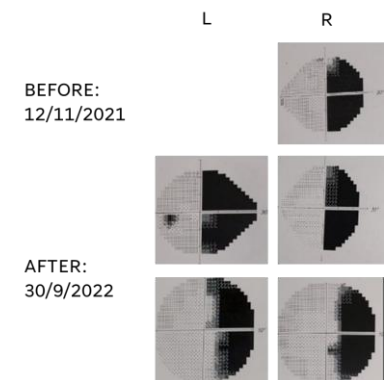


4

Revalidation
at home

5

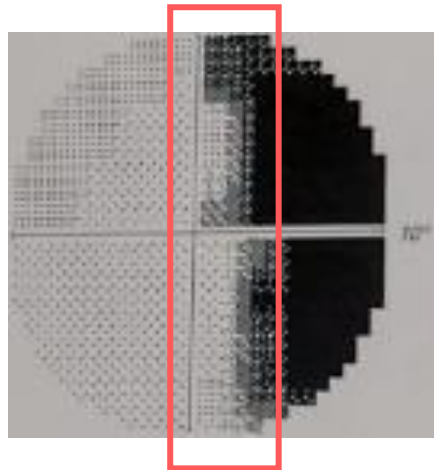
Measure results
in Oxford



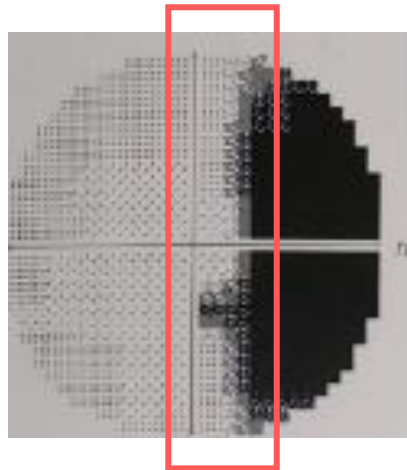
The results

Personal

15% gain in central vision field
= ability to read again



left eye



right eye

New best practices for HH revalidation

Article

Recommended Changes to Standard of Care for Monitoring of Cortically Blind Fields

Policy Insights from the Behavioral and Brain Sciences
2023, Vol. 10(2) 308–316
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Hanna E. Willis¹ and Matthew R. Cavanaugh^{2,*} 

Abstract

Global incidence of stroke has risen 70% in the last 30 years, affecting approximately 25% of adults throughout the course of their lives. Up to 60% of stroke survivors will suffer visual impairments, which significantly reduce quality of life and independence. Despite the high prevalence, patients are hugely underserved by the medical and research communities. Clinical care is variable throughout the United States and United Kingdom, with only 57% of patients receiving visual field assessments and 61% stating their need for support has not been fully met. Additionally, unlike stroke survivors with motor or language deficits, those with vision loss are rarely offered visual rehabilitation. This is despite recent research into the efficacy of visual training and the propensity for the visual deficit to worsen in the absence of an intervention. This article reviews common gaps in patient care and proposes policy changes to increase awareness of the condition, foster clinical and scientific advances in treatment, and enhance patient outcomes.

Keywords

stroke, vision, rehabilitation, perceptual learning, standard of care, hemianopia



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2026: next steps :

Research &
development



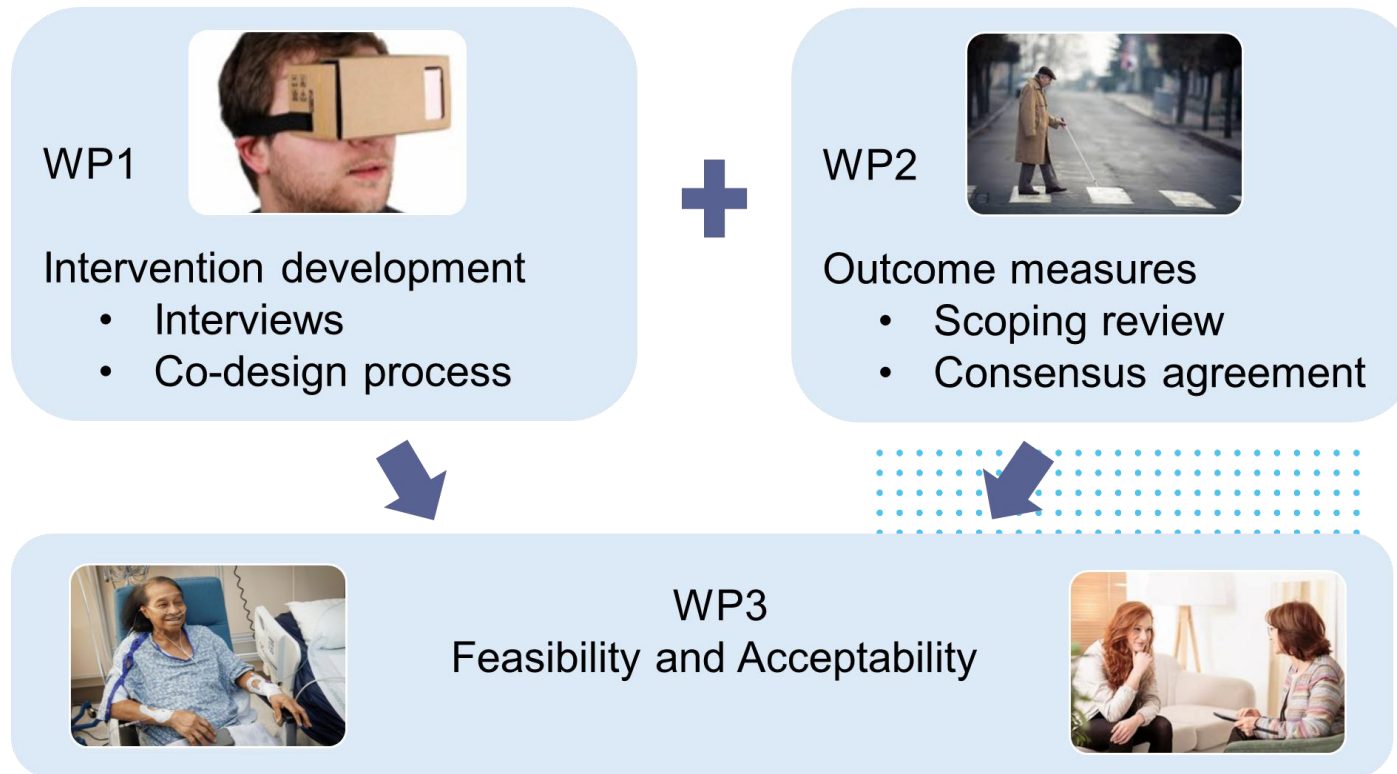
MOTION Study



UNIVERSITY OF
LIVERPOOL

New: take part in Motion study (2026)

Motion discrimination **T**rainning for v**l**visual field **I**oss after Bra**i**N injury



MOTION Study





**Let's make patient-centric
innovation happen.**

**Not just for patients,
but with patients. Together.**

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Thank you

