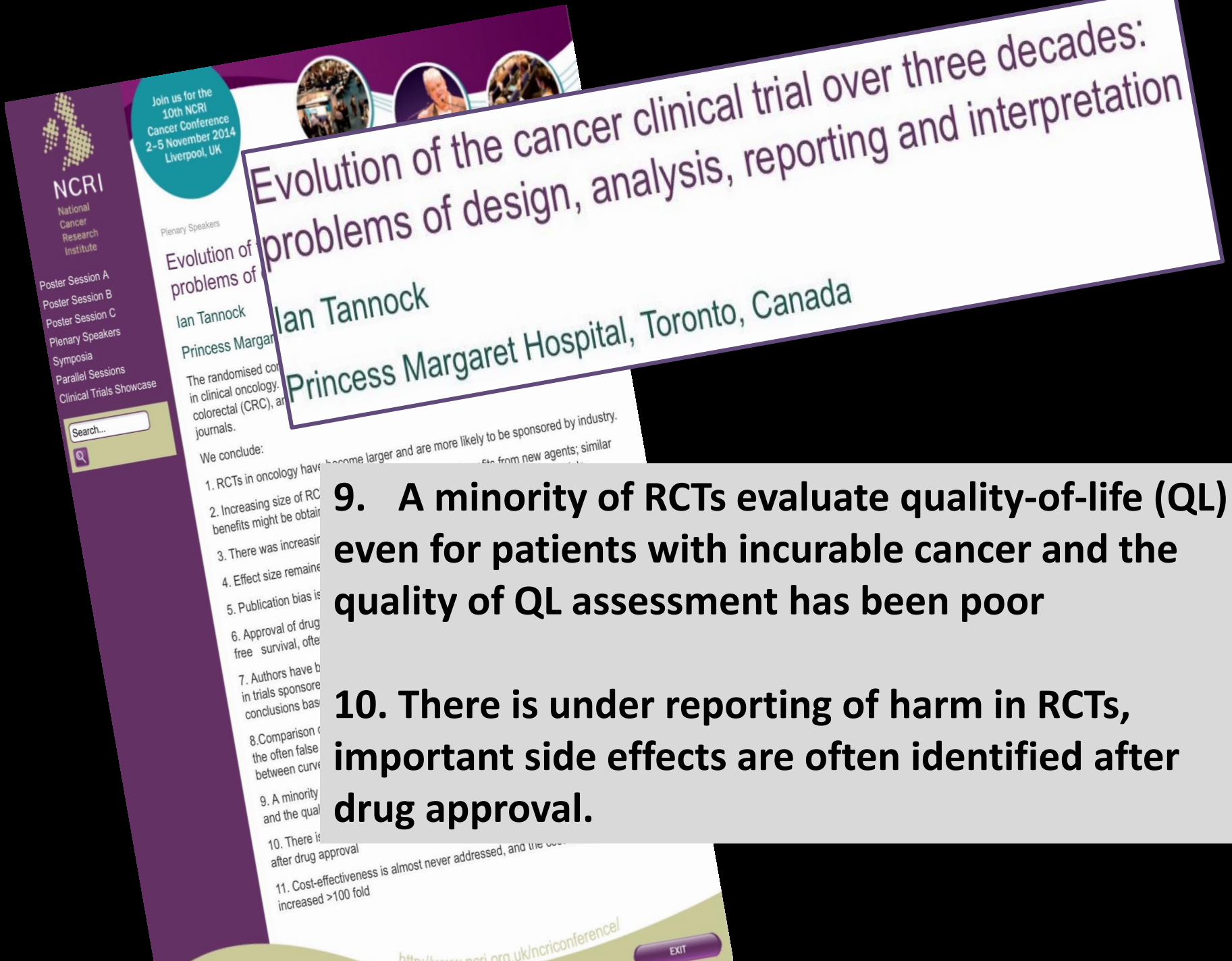
Quality of life - finding VALUE in research

Roger Wilson CBE

Sarcoma Patients Euronet


50%



9. A minority of RCTs evaluate quality-of-life (QL) even for patients with incurable cancer and the quality of QL assessment has been poor

10. There is under reporting of harm in RCTs, important side effects are often identified after drug approval.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to work, and perhaps it never will
Does the rhetoric so far outpace the reality that we risk fooling even ourselves?

Value =

Variations in
Actual
Life and
Usual
Experience

Fewer tools, easier to use

Compare outcomes between studies in same disease

Aggregate data

Longitudinal studies in standard care

Identify trends and pathways using ‘big data’

Feedback data to patients – treatment benefits

Make it impossible to ‘hide’ side effects

Regulators could manage interim approvals


COMET
INITIATIVE


EORTC


equator
network


SISAQOL Project


QORU
quality and outcomes of
person-centred care
policy research unit


UNIVERSITY OF
BIRMINGHAM


CPROR


COSMIN


ISOQOL
International Society for Quality of Life Research

Value =

Variations in
Actual
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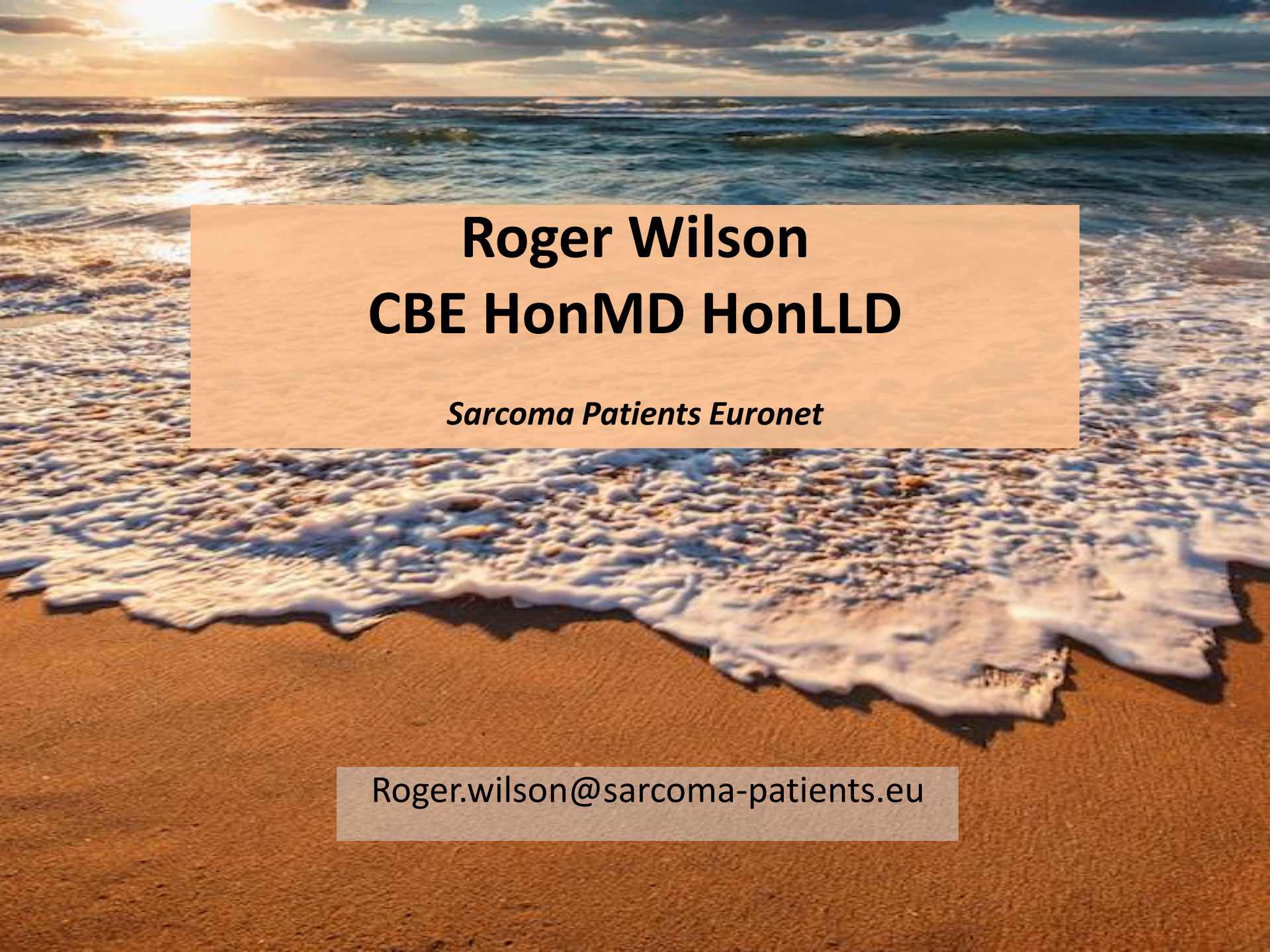
Experience



Roger Wilson
CBE HonMD HonLLD

Sarcoma Patients Euronet

Roger.wilson@sarcoma-patients.eu