

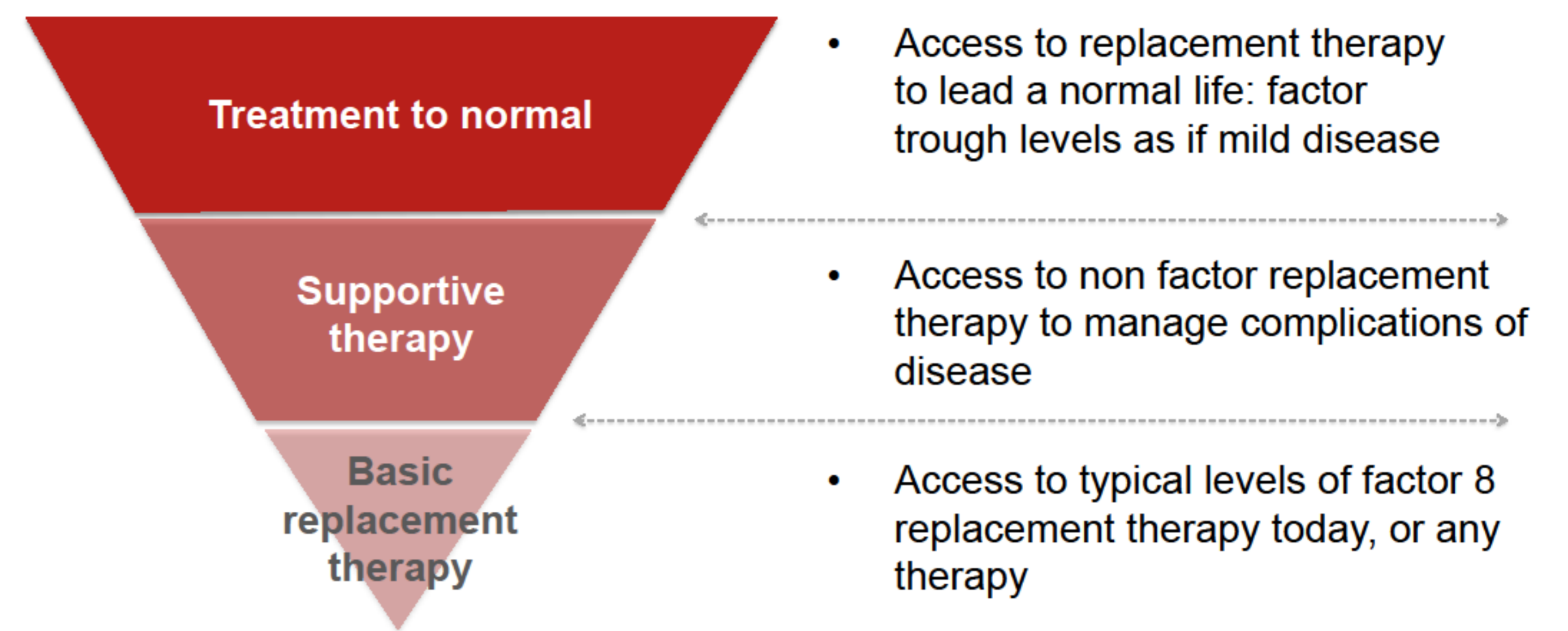
# A universal outcomes measurement system for improving care in hemophilia: Hemophilia Success Scorecard (HSS)

Dr. Richard Littlewood  
appliedstrategic, London, UK

## Introduction

- Treatment with replacement factors, although associated at one time with serious iatrogenic negative consequences, should today be relatively safe and effective
- In general, with better information systems and understanding of their importance, measuring outcomes in the treatment of disease has become more important
- Outcome measures are used to validate healthcare costs for many diseases
- Key to progress in this area is the availability of standard systems and tools to collect data and compared outcomes
- Currently, it is difficult to compare performance and results in hemophilia care in varying settings
- Significant questions on the economic value of, and approach to treatment in, hemophilia are outstanding
- A system with universal acceptance by patients, clinical and payer teams is needed.

## What to measure: what drives success in treatment?



## Aim

- Tools to measure outcomes**
  - A review of published evidence and expert opinion was completed to map current tools used to measure treatment outcomes
- Expert analysis of usefulness**
  - Review of measurement tools identified to assess usefulness, supported by expert physicians, nurses
- Analysis, recommendation**
  - A gap analysis of the current tools and drivers of outcomes, leading to recommendation for a new outcomes measurement system

## Methods

- A literature search was performed on PubMed, 23 April 2014, using search terminologies set up to identify sources of evidence potentially relevant to systems or tools used to measure treatment outcomes in hemophilia
- The search assessed for eligibility, matching at least more than two of the following criteria: *haemophilia/ hemophilia, outcomes, measure, treatment, system* (n=92), incorporating results from 2004 to date
- Sources of evidence (n=31) were reviewed to determine tools used to measure outcomes in hemophilia, according to predefined relevance criteria
- Discussions to validate results were held with a limited group of experts

## Results: tools to measure outcomes gathered from literature search

Measurements tools found: ten measurement tools were consistently, repeatedly found during the literature search:

Key Measurement	Outcomes Systems Used in hemophilia
Joint health/ physical activity	<ul style="list-style-type: none"> <li>• Hemophilia Joint Health Score (HJHS)</li> <li>• WFH Physical Examination Score (aka Gilbert score)</li> <li>• Hemophilia Activities List (HAL) and Paediatric (PedHAL)</li> <li>• Functional Independence Score in Hemophilia (FISH)</li> <li>• CHO-KLAT</li> </ul>
Quality of life	<ul style="list-style-type: none"> <li>• International Classification of Functioning, Disability and Health (ICF) and the International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY)</li> <li>• Haemo-QoL</li> </ul>
Adherence to treatment	<ul style="list-style-type: none"> <li>• Validated Hemophilia Regimen Treatment Adherence Scale--Prophylaxis (VERITAS-Pro)</li> </ul>
Workplace efficiency	<ul style="list-style-type: none"> <li>• Communication network, subjective knowledge, team roles, objective knowledge and partnerships (C-STOP)</li> </ul>

## Results: gap analysis

Limitations of the defined measurement tools were assessed to define the level of usefulness for current typical tools.

Analysis of Tools	Analysis of Metrics
<ul style="list-style-type: none"> <li>• No holistic system to measure outcomes</li> <li>• No agreed system that would be universal across national and international hemophilia centres</li> <li>• No comparable real time data</li> <li>• Too many different tools to measure aspects of treatment</li> <li>• Does not reflect modern outcomes (no bleeds)</li> </ul>	<ol style="list-style-type: none"> <li>1. Key drivers of treatment success not captured</li> <li>2. Lack of holistic picture of outcomes: the total patient view</li> <li>3. Current metrics not sufficiently patient-centric</li> <li>4. Metrics used only partially cover the disease</li> <li>5. Varied metrics for same goal used</li> </ol>

**Current approach to outcome measurement is not adequate: a universal consistent standard approach is required to meet modern hemophilia management challenges**

## Recommendation: outcomes measurement system in hemophilia

### Balanced Scorecard: hemophilia Success

Lead Metrics	CARE	RESOURCES	WELLBEING	SERVICES
	<ul style="list-style-type: none"> <li>• Average trough level for patient over 1/ y, average of all patients in care</li> </ul>	<ul style="list-style-type: none"> <li>• Average investment of resources per patient/ yr</li> </ul>	<ul style="list-style-type: none"> <li>• Per patient, average for all of Real time-assessed, standard QoL survey, 1/ y</li> </ul>	<ul style="list-style-type: none"> <li>• Patient care service satisfaction simple survey score</li> </ul>

## Recommended metrics: rationale, discussion

- Care**
  - Essential metrics of average trough levels of a patient with severe disease
  - Population (at a centre) average trough level, severe disease type
- Wellbeing**
  - Online, real time, once per year QoL measurement using standard tool like SF36 (or potentially Hem specific)
- Service**
  - Simple standard survey assessment of patient satisfaction with care provided at a centre
- Resources**
  - Average cost unit of clotting factor, per year at treatment centre
  - Average resources per patient (by disease type)

### Discussion

- The proposed measurement system is simplified and provides a real time patient and centre level assessment of treatment; the system is set for modern goals in hemophilia treatment (aim for normal?)
- The approach provides essential evidence of outcomes for the "whole" rather than research-type metrics based on selected systems

## Conclusions

- Initial view from assessment of published evidence indicates that there is a limit on useful tools to document outcomes in hemophilia
- A general approach for a universal system to measure outcomes in hemophilia care is suggested
- A simple scorecard approach which describes 4 key areas of outcomes is suggested
- The approach does not include many well known metrics/ systems; further research should be conducted to develop this suggested approach
- Outcome-led improvement in care (OLIC) can be achieved if a universal outcomes system is used; the major driver of outcomes is access to care. A radical step change in target levels of treatment would be suggested if this outcomes systems is adopted

## References

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