

The time to stop discussing RWE and start exploiting a range of data sources and applying advanced analytics

Adrian Jonas

Associate Director for Data and Analytics

The beginning: why NICE was set up

- Established in 1999
- Aim: to reduce variation in the availability and quality of treatments and care (the so called 'postcode lottery' in the UK)
- To resolve uncertainty about which medicines and treatments work best and which represent best value for money for the National Health Service [NHS]



Then and now

1999



2019



Types and functions of NICE guidance



- **Technology appraisals – entry to NHS funding**
 - largely new pharmaceuticals
 - robust economic analysis
- **Guidance – advice on best practice**
 - **Devices and diagnostics - cost-effectiveness**
 - **Medical technology guidance – cost saving**
 - **Guidelines – medical conditions and symptoms, public health and social care**
- **Interventional procedures – represents a ‘licence’ to use**
 - safety and efficacy

Core principles of NICE guidance

- Comprehensive evidence base – not just RCTS
- Expert input - from clinicians, economists etc
- Patient and public involvement
- **Independent advisory committees**
- Genuine consultation with all stakeholders
- Regular review and updating
- Open and transparent process – meetings held in public.



But sometimes there are problems with the evidence...

- Not enough
- Poor quality
- Conflicting
- Wrong sort

“Evidence is inherently uncertain, dynamic, complex, contestable, and rarely complete”

Lomas, J; Culyer T et. al

Conceptualizing & Combining Evidence For Health System Guidance; CHSRF, May 2005

NICE therefore has already utilised a variety of other data sources

Evaluating technologies

- Cancer Drugs Fund
- Commissioning through Evaluation
- Industry submissions
- Datasets to answer specific questions, eg databank for MiniMed
- Registry data for products

Developing guidelines

- Routine use of published reports based on electronic health records
- Occasional bespoke analysis of broader data, usually linked to economic analysis

Assessing impact

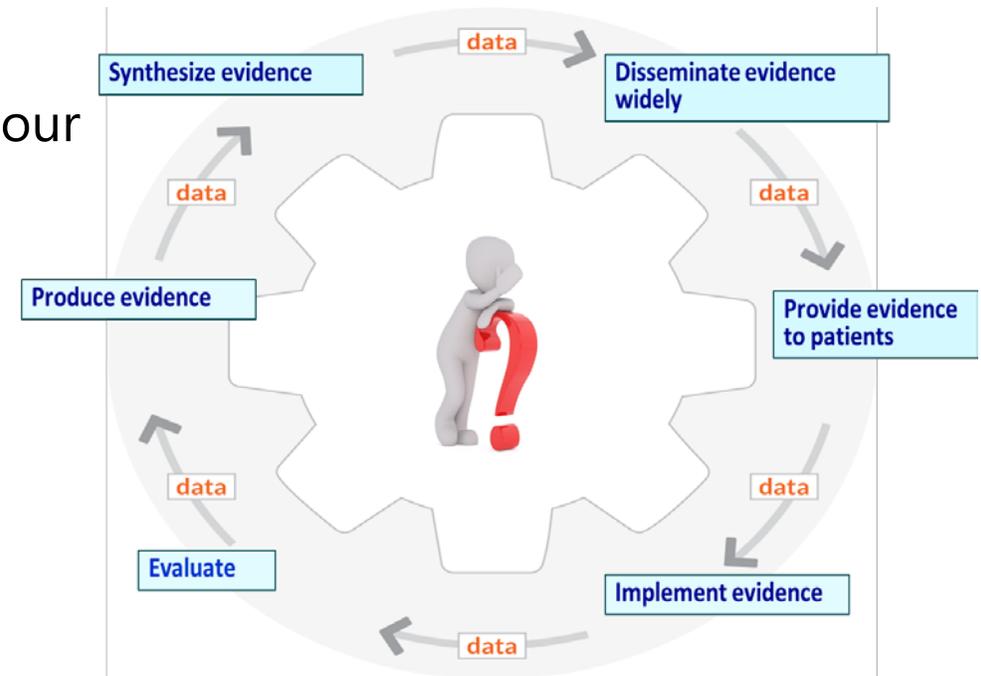
- Digital therapies and IAPT
- Resource impact assessment
- Innovation Scorecard estimates
- Guidance uptake

But what's in a name?

- There is much variation on what sources the term 'Real World Data' includes and doesn't include
- Important contributions from [GetReal](#), ISPOR, NICHSR etc
- GetReal's definition of RWD: 'An umbrella term for data regarding the effects of health interventions (e.g. safety, effectiveness, resource use, etc) that are not collected in the context of highly-controlled RCTs
- We shouldn't try to define RWD, but instead simply indicate that:
 - ***Guidance developers will undertake analysis on a variety of different types of data to develop evidence to inform our work***
 - ***the suitability of the data will be determined by the nature of the question that the evidence will inform***

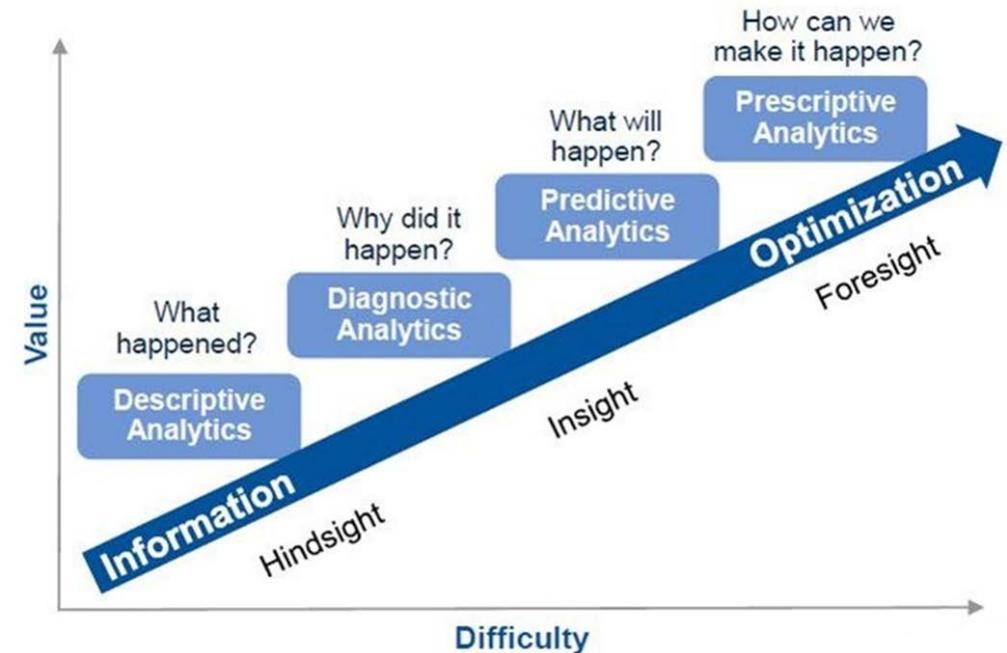
NICE's ambition for future use of data and applied analytics in guidance development

- **Develop and update guidance more rapidly** than we can achieve currently;
- Provide **answers to questions that we cannot answer** using our traditional approaches
 - Extrapolation beyond clinical trials – predictive effectiveness
 - Validation of intermediate outcomes
- Measure the effectiveness of interventions in **real-world settings**;
- Improve our **tracking of guidance implementation**, uptake and impact, and use of this information to inform the need to update.



NICE's ambition for future use of data and applied analytics in guidance development

- Unlock and exploit the full potential of data;
- Develop a range of partnerships;
- increase capability to link live systems and unstructured data;
- translation of data into evidence.



Not revolution in many ways but ensuring we embrace technological advances to improve our evidence base

Statement of intent for data analytics

Developed through internal collaboration and consultation, discussion with key external partners. It covers:

- **What kind of evidence NICE currently uses to develop guidance**
- **What broader types of data are available**
- **When and why should broader types of data be considered**
- **Practical considerations associated with data analytics**

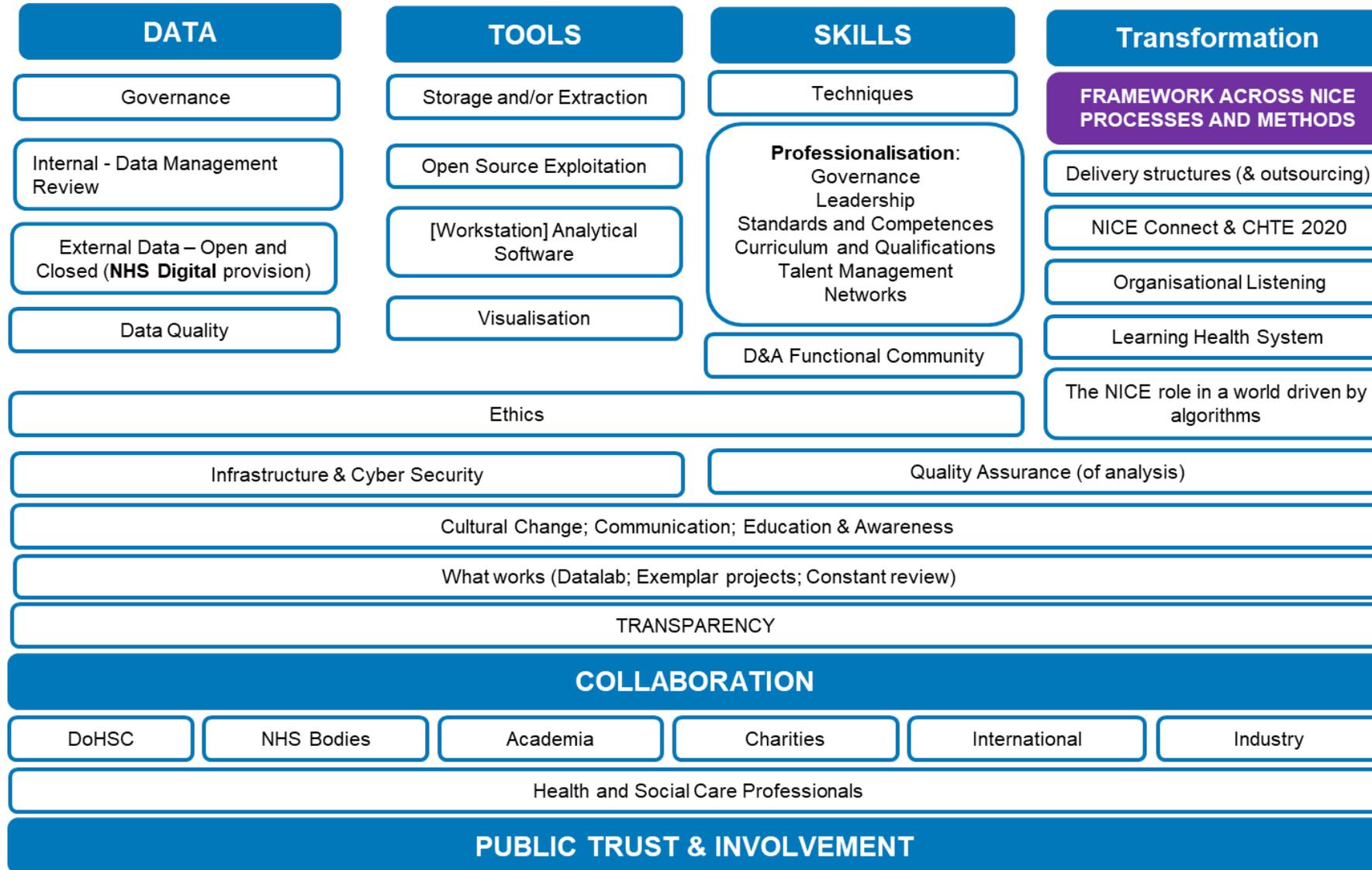
Technical detail on methodological considerations are not included in the statement and will be developed at a later stage.

Key challenges for NICE

- Access to data, including data governance
- (Poor) Data Quality
- Capability and capacity to frame the questions and to carry out any analysis
- Understanding when to use data exploitation – when is it an acceptable (or better) alternative to traditional research
- Recognising a high quality analysis

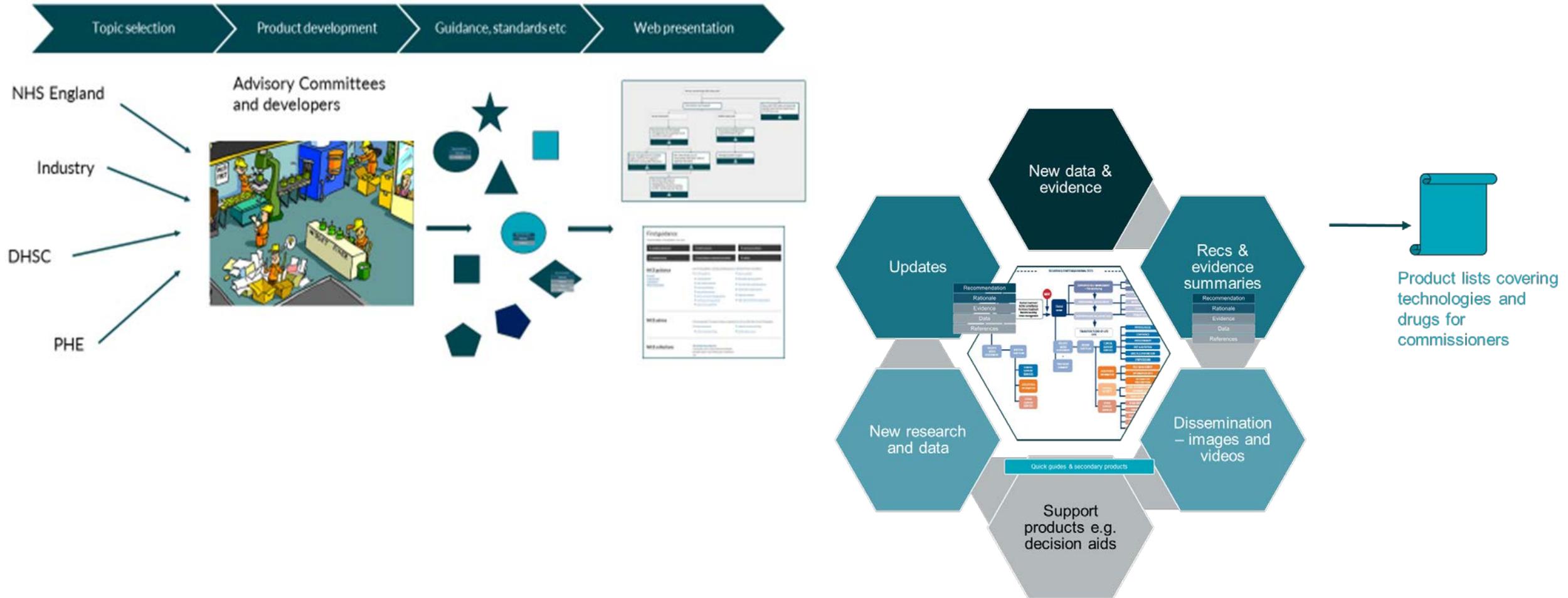


Implementation will therefore require evolution across the whole ecosystem...



And a crucial part of Transformation across NICE

A shift in thinking towards a dynamic process of developing advice directly into online interactive pathways



The opportunities are sensational...

- New Technology aimed at assisting Healthcare Delivery (clinical decisions/recommendations, management of resources etc.)

