



**“Not all that is measurable is of value, and not all that is of value can be measured”**

Bradley and Field 1995 Evidence Based  
Medicine, Lancet 346:8338–839



Face to face workshop

### **Asthma**

Airways Group

May 2014 – October 2014

**Partners:** Asthma UK,  
(Patient and Professional  
members)



Online survey

### **Sinusitis**

Ear Nose Throat Group

October 2014 – March 2015

**Partners:** ENT UK,  
Professional organisations,  
no patient group for  
sinusitis



Experiential data from online  
collection

### **Breastfeeding**

Pregnancy and Childbirth  
Group

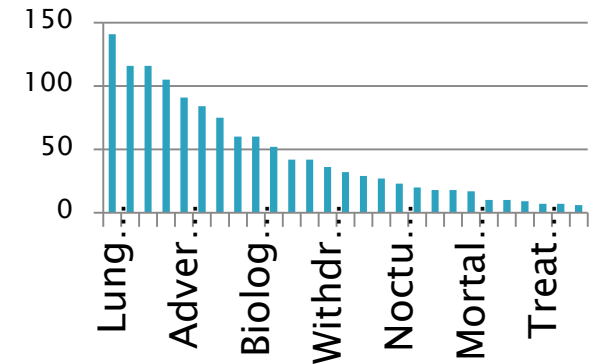
July 2014 – January 2015

**Partners:** Healthtalk, Health  
Experiences Research Group  
Oxford University, National  
Childbirth Trust,  
Breastfeeding Network

**Overview: Outcomes Important to Patients, Public and Practitioners**

# Evaluation

- ▶ What were the important **outcomes** from each pilot?
- ▶ Correlate to **existing outcomes** used by the review group?



- ▶ What has the **engagement activity** delivered for the review group?
- ▶ Practical considerations; costs, skills and support needed, if we did it again.....

# Key results



**'Unexpected' Asthma UK  
Facebook survey**

**Face to face workshop**

18 people participated

69 outcomes described

Some overlap with  
outcomes used in Asthma  
systematic reviews.  
Important outcomes  
symptoms, quality of life,  
flare ups, adherence



**Online survey**

235 people participated,  
155 practitioners, 80  
people with sinusitis

**549 'in scope' outcomes  
generated**

73% of these concerned  
symptoms (sino nasal and  
general), expressed by both  
patients and professionals



**Secondary analysis of  
breastfeeding Healthtalk data**

51 interview transcripts,  
independently assessed x 2

Generated 15 outcome  
themes

More diverse than outcomes  
used in breastfeeding  
reviews, some correlation

Unable to ID important  
outcomes

# Focus on communication in **workshop**



Depth

- of meaning, context and different perspectives of outcomes

Language

- different when talking about same thing!
- developing shared understandings e.g. 'Asthma Control'

Challenge

- 'thinking differently' outside the medical model
- more participant control of the agenda

# Focus on social media online survey



Core message

**U know your nose best!**

Use  
imagination  
take risks

Plan route to  
survey

**Have a conversation...**

ID optimum  
days and  
times

Plan variety of  
delivery




# Focus on challenge of using experiential data – online source

Healthtalk proved a rich source of potential outcomes material....

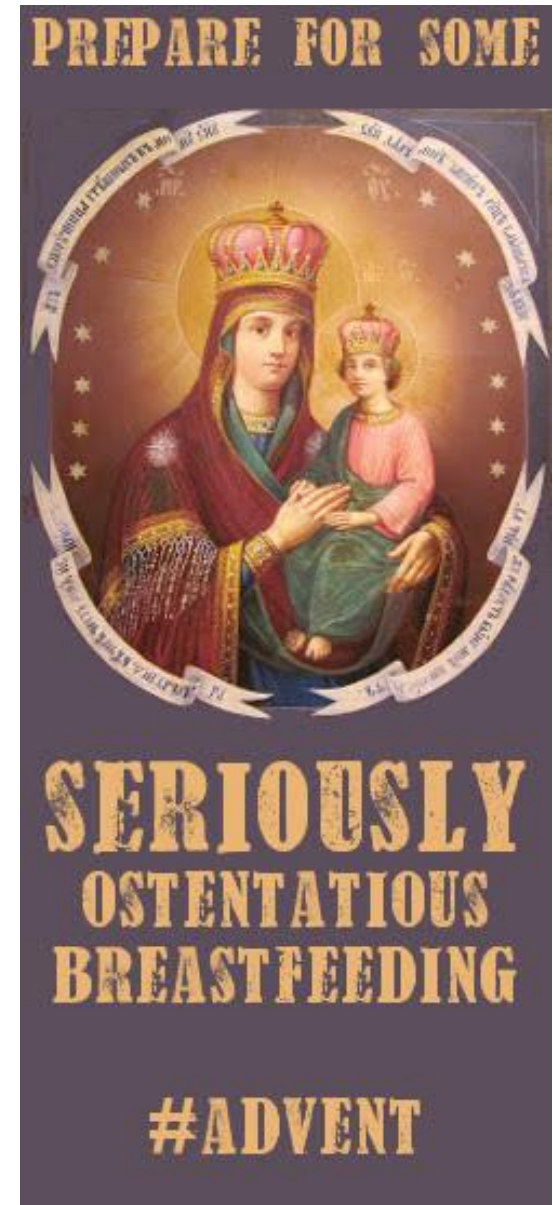
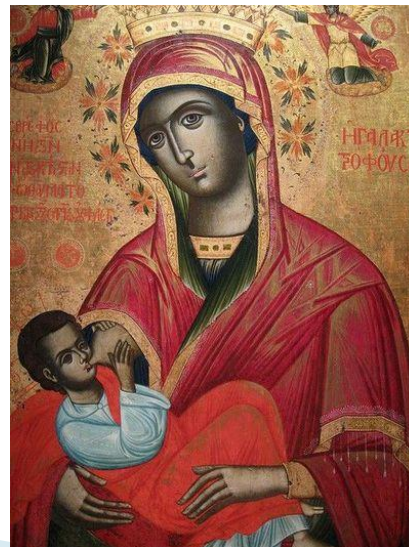


Some was obvious; 'aspirations for breastfeeding', 'measures of success' ....



Less explicit: emotional issues wrapped up in breastfeeding e.g. falling short of (self, family, societal) expectations, feeding in public.....

# Feeding in public – #ostentatious breastfeeding



# Reflections

*"I wouldn't want healthcare professionals to think those outcomes are any less important because, believe me, when you suffer from the sleep deprivation as I did (due to being unable to breath at night through my nose lining swelling up), my quality of life was fast approaching NIL" (patient)*

Is "what is important to me?" the right question to ask about outcomes for people?  
This may bias them not to talk about more functional outcomes.  
Health Professional

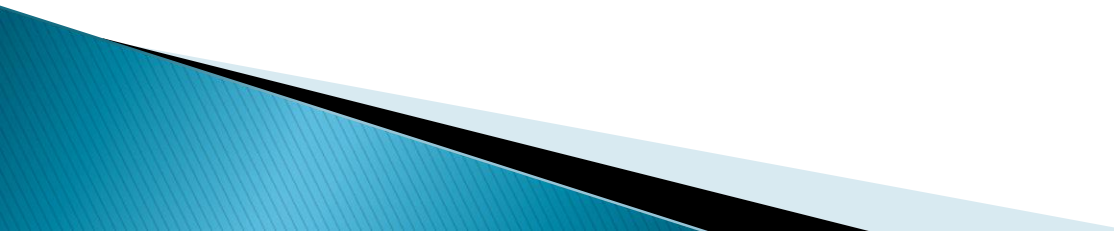
*"Particularly enjoyed the reactions to the outcomes discussion and the small group work" (patient)*

***"It validated our current strategy to have primary and secondary outcomes that are a mix of clinical and objective and more subjective outcome measures"***  
Review group member

***"I started the day feeling defensive I ended feeling as though I had learned a great deal and feeling more positive about building on the qualitative work - thanks very much".***  
Reviewer

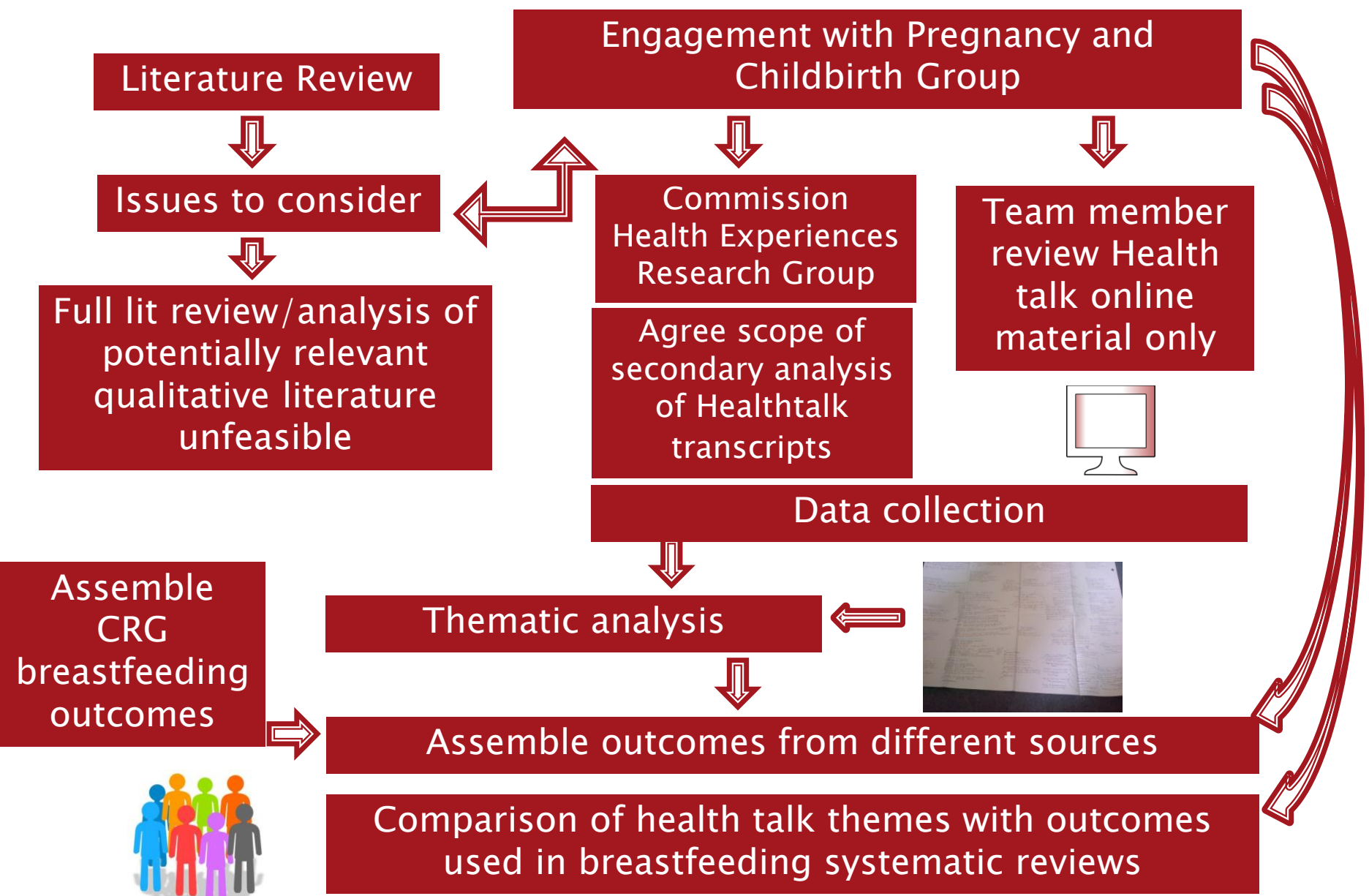
***"it is quite scary"***  
***(engaging with patients)***

# Take home messages?

1. We were able to gather and discuss **relevant outcomes** for systematic reviews, in all 3 pilots
  2. **Simple online surveys** a cost effective option for 'testing the water' of preferred outcomes
  3. **Social media** can reach interested public
  4. Workshops offer **context and depth** for talking about outcomes, but are resource heavy
  5. **The leap** from the relevance of online experiential data to systematic review outcomes is a big one...
  6. More **evaluation of engagement activity** in outcomes development for systematic reviews
- 

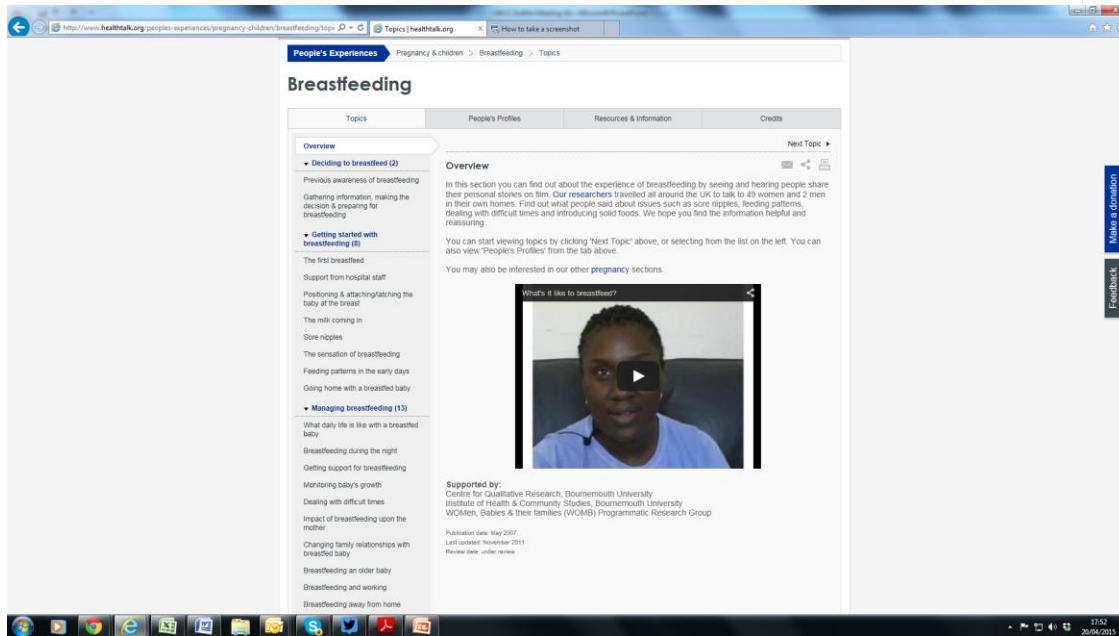
**Old slides use if needed  
for clarification**

# Using an online source – breastfeeding



# Breastfeeding –using an online source

## www.healthtalk.org



Review Title	Number of full text downloads
Early skin-to-skin contact for mothers and their healthy newborn infants	13,376
Midwife-led continuity models versus other models of care for childbearing women	9,677
Effect of timing of umbilical cord clamping of term infants on maternal and neonatal outcomes	8,458
Optimal duration of exclusive breastfeeding	6,252
Support for healthy breastfeeding mothers with healthy term babies	5,916

- ▶ Respect
- ▶ Decision making
- ▶ Developing role as mother
- ▶ Support (overarching principles, early, peer, community)
- ▶ Benefits (mum, baby, bonding)
- ▶ Routine, sleep
- ▶ Practical techniques
- ▶ Monitoring weight
- ▶ Management in challenging circumstances
- ▶ Managing difficulties in feeding
- ▶ Impact on relationship
- ▶ Managing return to work, sharing childcare
- ▶ Cultural and emotional impacts
- ▶ Antenatal preparation (considering feeding, practical and managing at home)

Healthtalk outcome themes

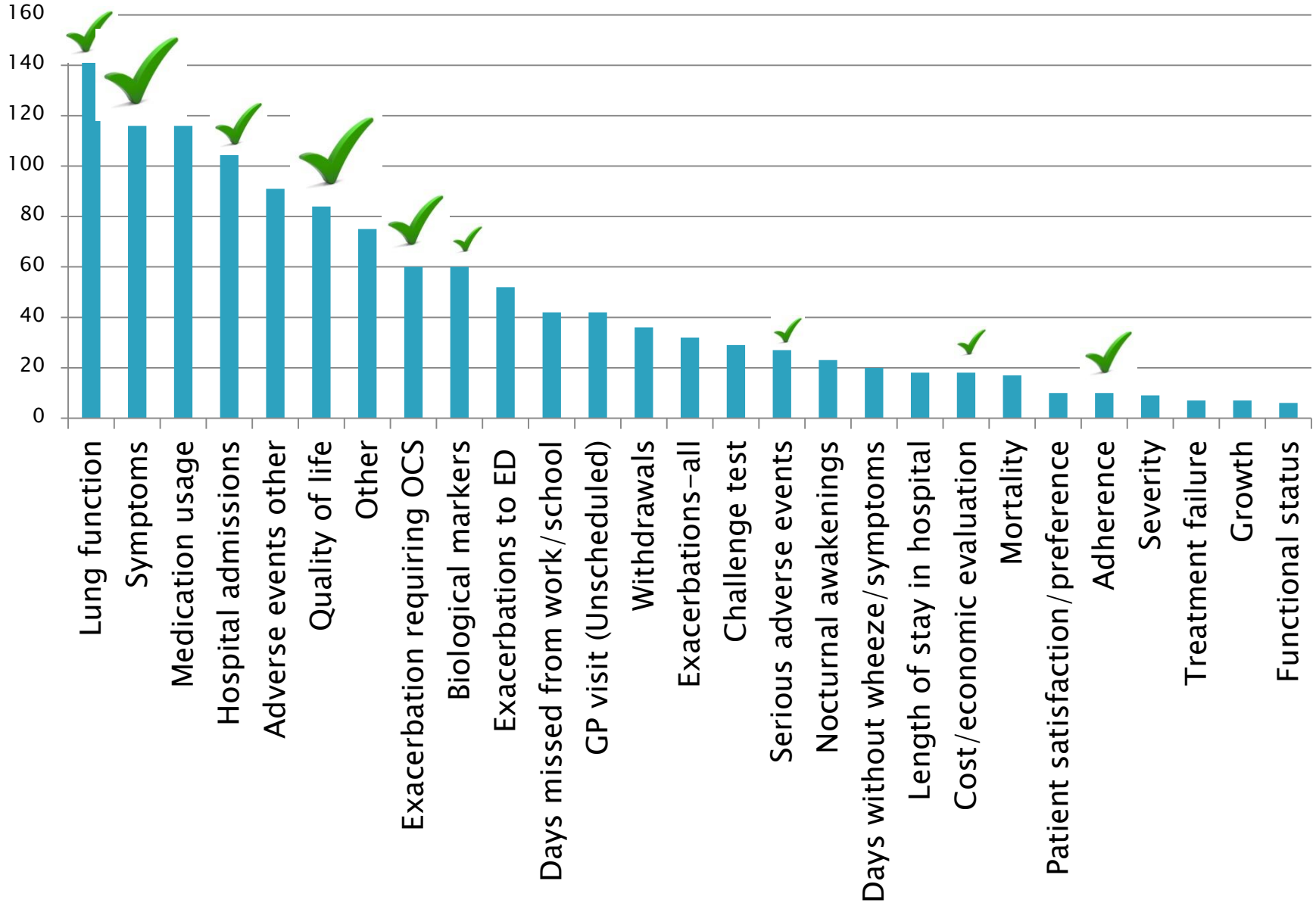
- ▶ Measures of breastfeeding, e.g. incidence, duration, proportion, prevalence, rates
- ▶ Objective outcomes for baby e.g. growth, development, morbidity, mortality
- ▶ Objective outcomes for mother e.g. weight loss, amenorrhea and chronic diseases
- ▶ Benefits to baby e.g. prevention of conditions in child and subsequent adult chronic conditions

CRG outcome themes

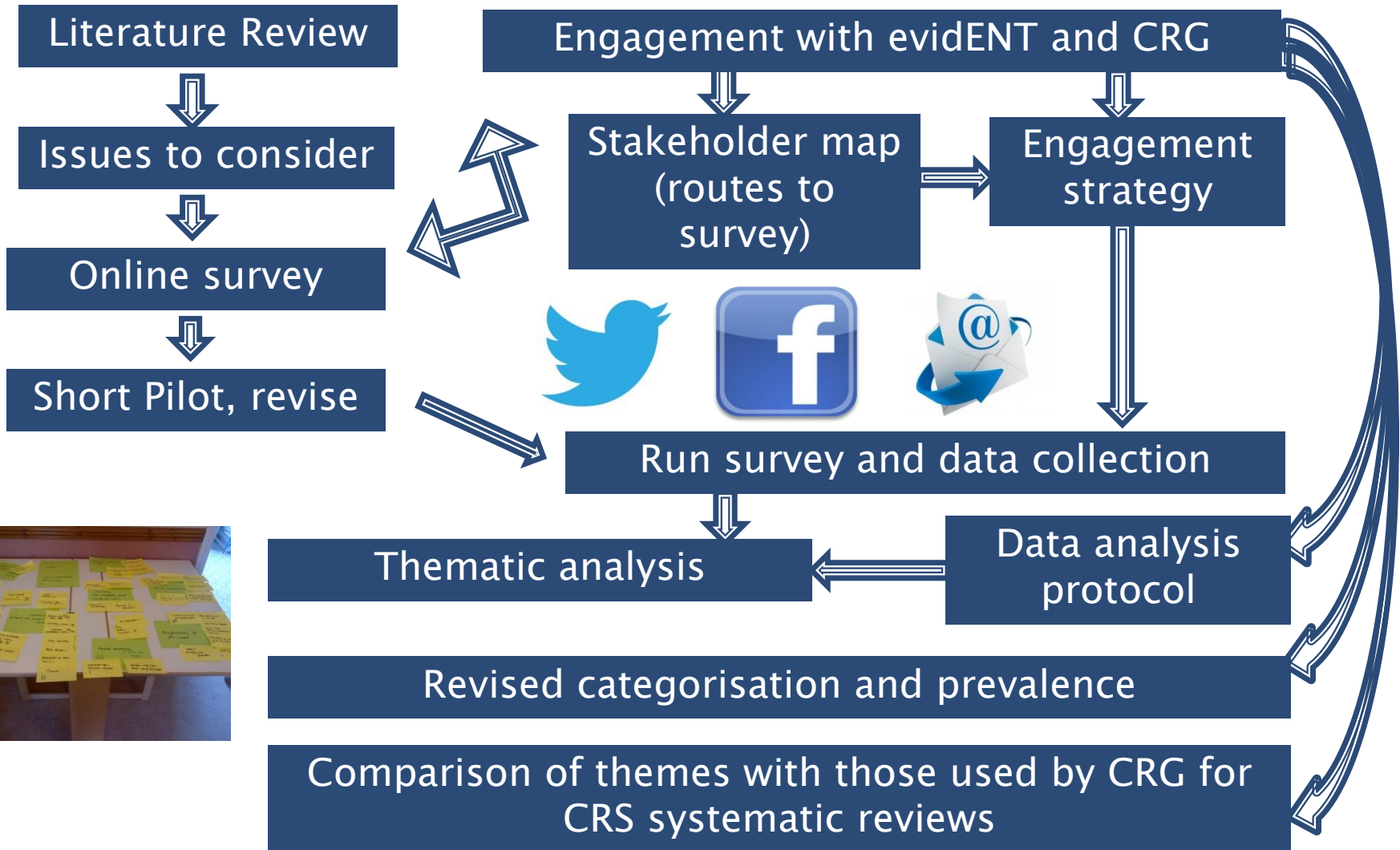
# Workshop development – asthma



# Which workshop outcomes matched?



# Survey development – sinusitis





# Which survey outcomes matched?

