

Confidential Inquiry into  
premature deaths of people  
with learning disabilities (CIPOLD)

Final report

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- **2004**  
**Treat me right!**
- **2007**  
*Death by Indifference- 6*
- **2009**  
**NHS ombudsman's report**
- **2010** **NHS progress report**
- **2012**  
*Death by Indifference-74*  
*Winterbourne*
- **2013**  
**CIPOLD report**

**Poor decision making a  
consistent theme**

# Enables compliance with 3 national legal and clinical frameworks

2005 Mental Capacity Act

2007 BMA/RC/RCN statement on  
CPR decisions

2011 NHS guidance on  
advance care planning

**[www.cnne.org.uk](http://www.cnne.org.uk)**

Click on *Deciding right*  
signpost

*Deciding right*

## Your life Your choice

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An integrated approach to  
making care decisions in advance  
with children, young people and  
adults

- **2005 Mental Capacity Act**
- **2007 BMA/RC/RCN statement on CPR decisions**
- **2011 NHS guidance on advance care planning**

**The best legal and clinical frameworks**  
**...but complex, lengthy and...ignored**



# National initiatives which make no mention of the MCA

DH *Essence of Care* (2010)

Prime Minister's *Dementia Challenge* (March 2012)

DH *Mandate to NHS Commissioning Boards* (April 2013)

DH *Helping people make informed choices about health and social care* (March 2013)

NHS England draft *Transforming Participation in Health and Care* (August 2013)

Winterbourne Review Improvement Programme 2013

GMC: the current *Good Medical Practice* 2013

Neuberger panel report on the LCP July 2013

NICE scope *Older people with long-term conditions*  
February 2014





# Challenges



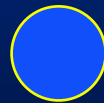
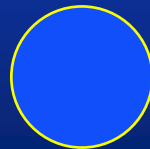
**Shared  
decision  
making**

**Advance  
care  
planning**

**No decision  
about me,  
without me**

# Shared decision making

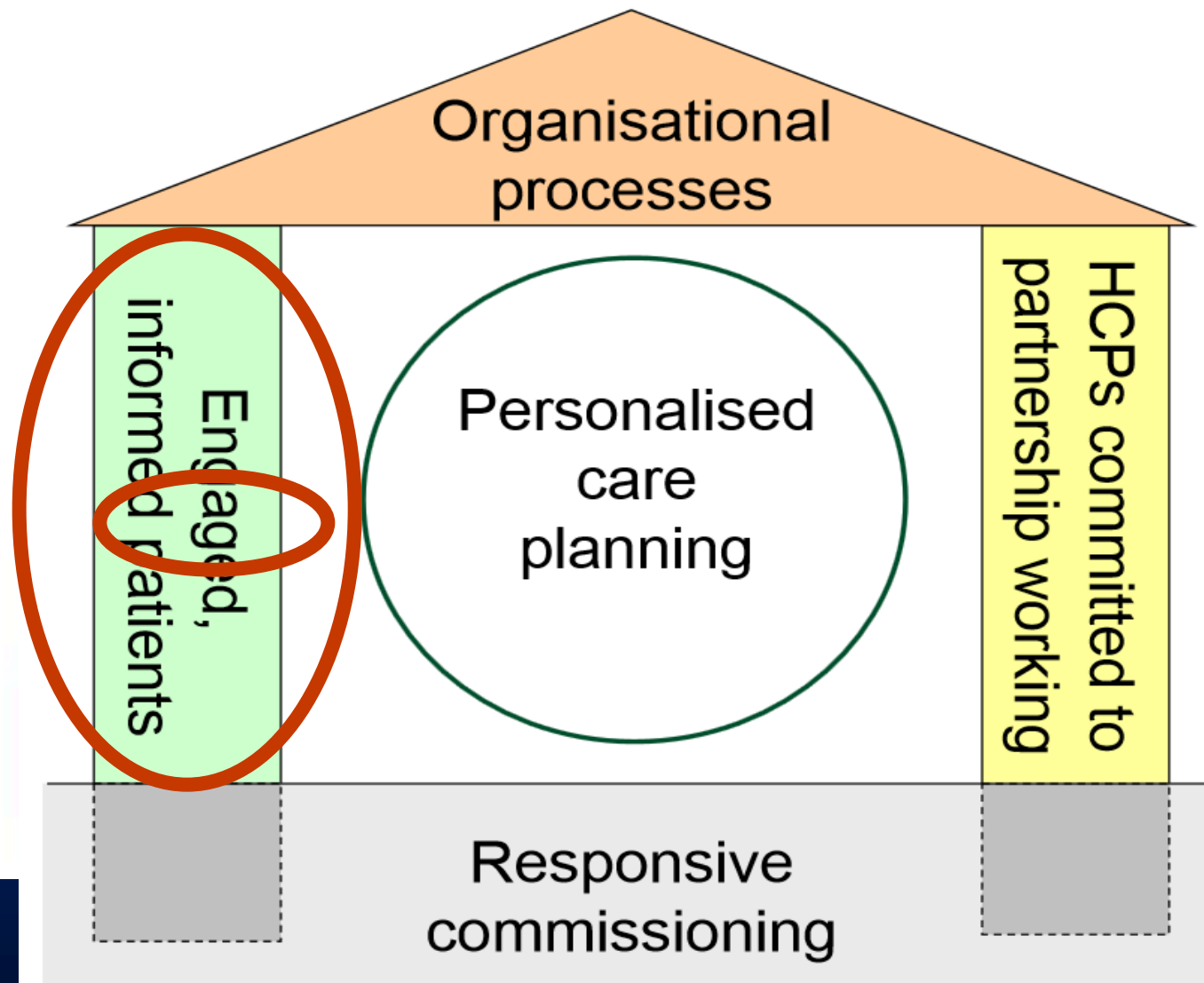
= a dialogue  
between  
two  
experts....



the individual  
and  
the health or  
social care  
professional



# Shared decision making





**Sticking  
points**

# Best interests

**The health or  
social care  
professional's  
expert opinion  
based on the  
individual's  
circumstances**

**With capacity =  
Shared Decision  
Making**

**Without capacity =  
MCA best  
interests process**

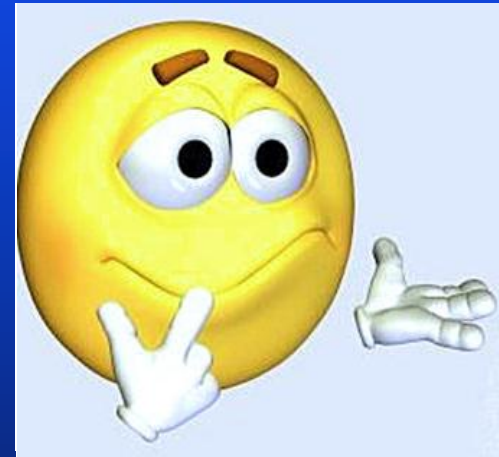
**Continuous dialogue**

# Familiarity with MCA components (2012/3, acute trust)

**100%** of staff said that they  
had at least some idea of the  
Mental Capacity Act

but

**only 15%** knew what the MCA  
meant by best interests



**What people think they know is not  
what they actually know**





### **3 Practice principles**

- 1. No doubt about capacity  
= obtain consent**
- 2. Doubt about capacity for  
this decision  
= test capacity**
- 3. Capacity lacking for this decision  
= MCA best interests process**



# A little help....

- Helps with making decisions in advance
- Includes DNACPR decisions
- Includes children & young people
- Does not advise treatment

**[www.cnne.org](http://www.cnne.org)**  
**Click on Signpost**



# Emergency Health Care Plans

- Individualise emergency decisions
- Can make clear that all treatment should be considered
- Decision-making aid



**NHS**

This EHCP contains information to help communication in an emergency for the individual, to ensure timely access to the right treatment and specialists  
This form does not replace a DNACPR form, advance statement or ADRT  
 Copies of this document cannot be guaranteed to indicate current advice- the original document must be used

Name of individual: NHS no:  
 Address: Date of birth:  
 Postcode: Hospital no:  
 Next of kin 1: Phone: Relationship:  
 Next of kin 2: Phone: Relationship:  
 For children and young people, who has parental responsibility?

GP and practice details:  
 Lead nurse: Place of work: Tel:  
 Lead consultant: Place of work: Tel:  
 Emergency out of hours Person or service Tel:  
 Other key professionals: Place of work: Tel:  
 Place of work: Tel:  
 Place of work: Tel:  
 Place of work: Tel:

Underlying diagnosis(es): For children: wt in kg Date

Key treatments and concerns you need to know about in an emergency  
 (eg. main drugs, oxygen, ventilation, active medical issues)

Important information for healthcare professionals (if necessary use p3 for additional information)

EMERGENCY HEALTH CARE PLAN (EHCP) v1.4

# EHCPs- need thought

- New concept in adult care
- Some think it only limits care
- Often wrongly named 'ceilings of care' or 'escalation of care'
- Uncertainty about what to write





## Risks



# Risks

- MCA has been law since 2005
- Some advice on advance decisions is confused
- Healthcare discrimination persists



**Doing nothing is not an option**

**Best Interests  
process**

**Emergency  
anticipated**

EHCP +/- DNACPR

**Emergency**  
Treat if possible

*If capacity  
has been  
lost*

**If capacity is  
present but a  
loss is  
anticipated**

- Advance Statement
- ADRT
- Personal Welfare LPA

The decision of the  
individual with capacity  
usually takes precedence  
over any other decision

**Person-centred Dialogue  
(Shared Decision Making)**



