

# Service Improvement Project

## *Epilepsy Passport*

George Darling, Matthew Hodgson, Peter Sudworth, Amy Szuman



# Initiate

- Project brief
- Model for improvement
- Identifying stakeholders

## INITIATE

Drivers for Service Improvement

Service Improvement Matrix

Change Management

Leadership

Stakeholder Analysis

Patient and Public Involvement

Contracting (PM)

Project Brief (PM)

Daily Log and Lessons Log (PM)

Sustainability Diagnostic Tool

# SIP Brief

- To design and implement a standardised epilepsy care plan to fulfill aspects of the 2012 NICE guidance on management of epilepsy in primary and secondary care<sup>[1]</sup>.
  - Study by RCPCH indicated a lack of sharing of information<sup>[2]</sup>
  - The “passport” will be developed following initial patient diagnosis and consultation – using RCPCH template.
  - To standardise and improve patient care and experiences

# Epilepsy

- A group of chronic neurological conditions characterised by recurrent seizures.
- Many different types of seizure
  - Absence / Tonic-Clonic / Simple Focal
- Patients vary drastically in severity
  - Longer than 5 minute seizures require rescue medication
- Most common in children under 16y

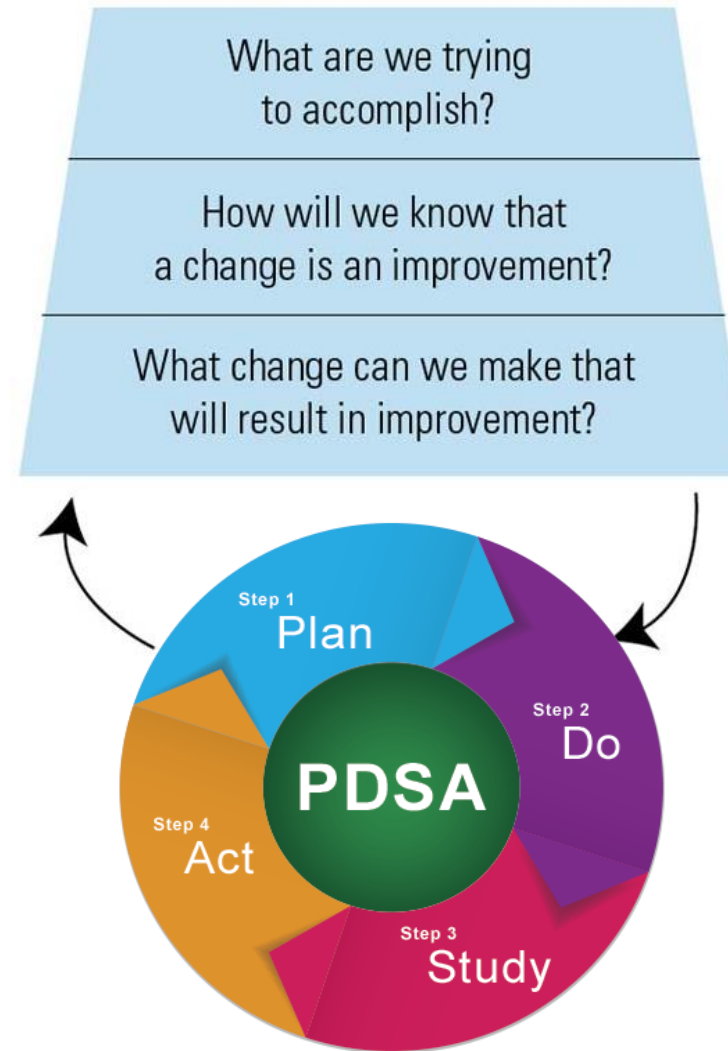
# The Passport



**Epilepsy Passport**  
Communicating my condition

**RCPCH**  
Royal College of  
**Paediatrics and Child Health**  
*Leading the way in Children's Health*

# Model for Improvement



# Stakeholders

	High Impact	Low Impact
High Power	Consultant Pediatricians Epilepsy Nurses	Trust board CEO
Low Power	IT Department Patients Parents	Secretaries GPs Emergency Care Doctors Schools



# ENGAGE

- Initial stakeholder contact
- Necessity for an epilepsy passport

## ENGAGE

Ice Breakers

Influencing Stakeholders

Communication and Creating Rapport

Clinical Microsystems

Facilitation and Conflict Management

Wheel of Multiple Perspectives

Leadership

ATE

Service Improvement  
ment Matrix

# Necessity

- National Institute of Clinical Excellence - NICE (2012).
  - Epilepsies: Diagnosis and management (CG137).

# NICE Quality Standards

- 9 quality standard recommendations by NICE, two of which were relevant to the implementation of an epilepsy passport.
- **ALL** children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.
- Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

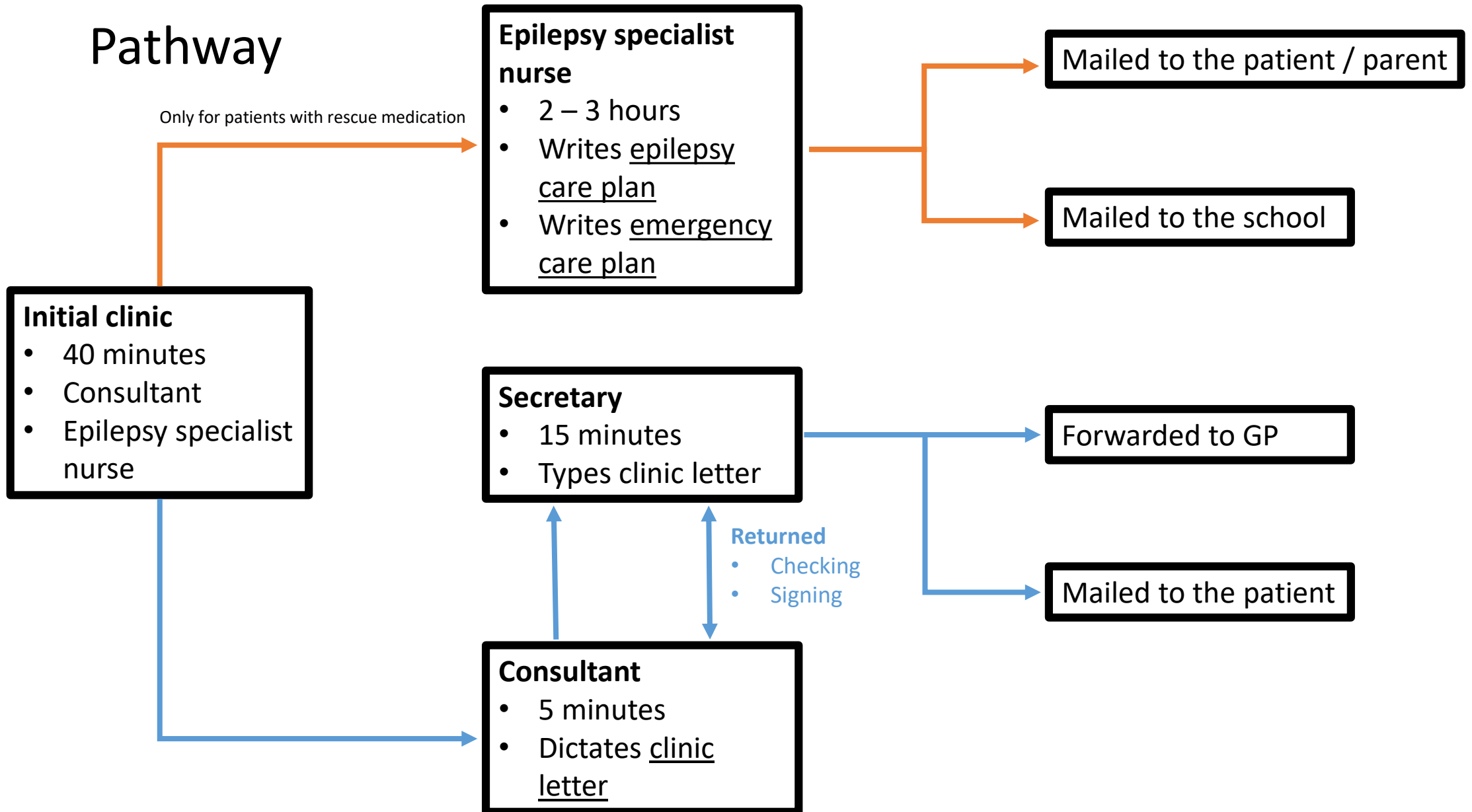
# DIAGNOSE

- Process mapping
- Patient questionnaires
- Interviews
- Focus groups

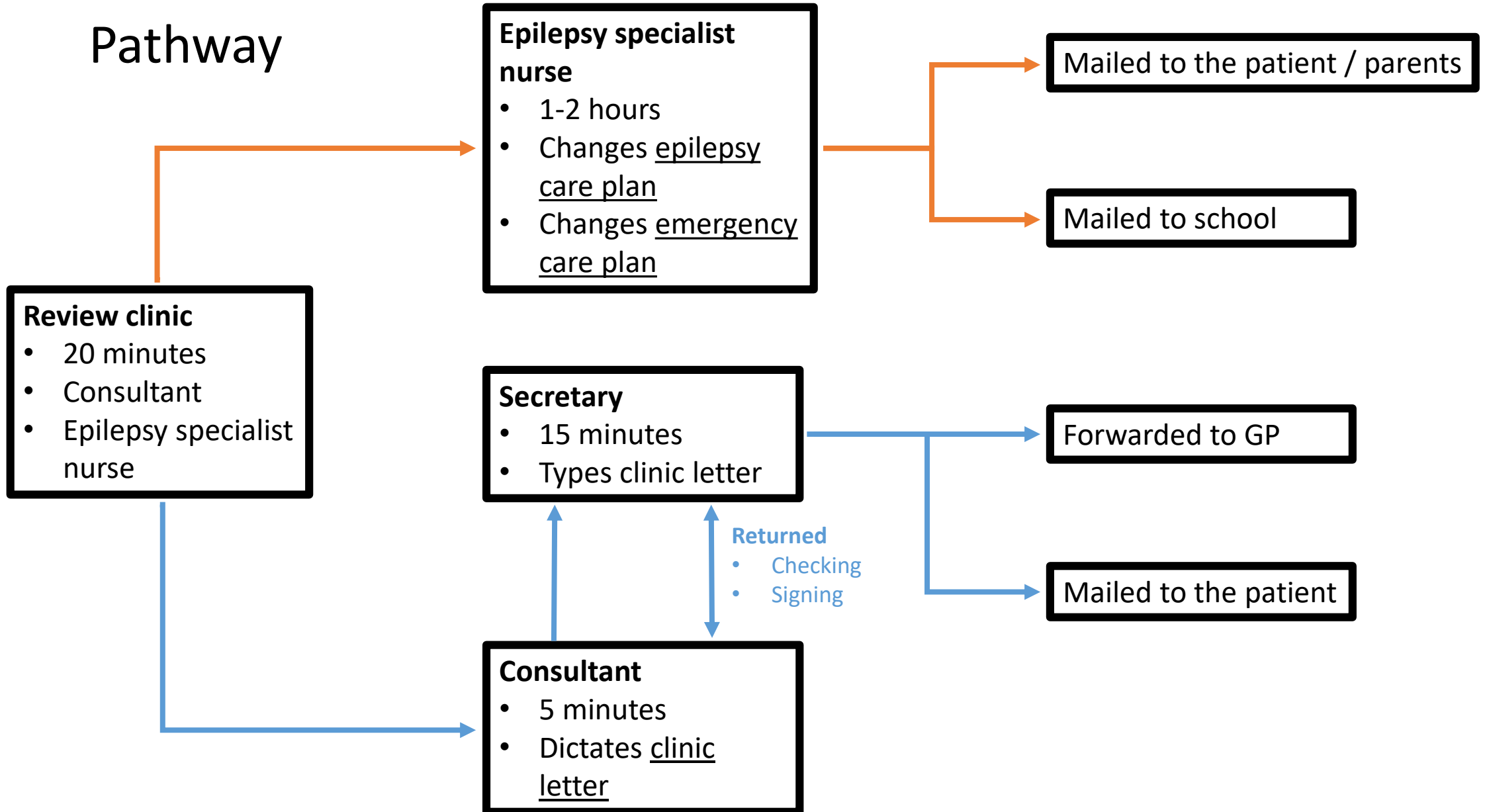
## DIAGNOSE

Measurement for Improvement  
Benchmarking  
Statistical Process Control (SPC)  
Appreciative Inquiry  
Lean Thinking  
Process Mapping  
Theory of Constraints  
Capacity and Demand (C&D)  
Problem Analysis  
Patient Walkthroughs  
Questionnaires  
Cause and Effect (Fishbone Diagram)  
Patient Diaries  
Interviews  
Clinical Audit  
Focus Groups

# Current Initial Pathway



# Current Review Pathway



# Identification of problems

- Some patients get very little information
- A number of complex information pathways
- No standardisation
- Room for errors and missed information
- Little communication between consultant and epilepsy specialist nurse
- Lots of additional time required for creation of individual care and emergency plans
- Additional time requirements on ESN for unforeseen care plans

# Current cost

- £102.09 per initial consultation
- £59.47 per review consultation
- Epilepsy specialist nurse cost is disproportionate
- Subpar system
  - Less than full coverage currently
  - Unfeasible when following NICE guidelines



# Current Situation: Questionnaire

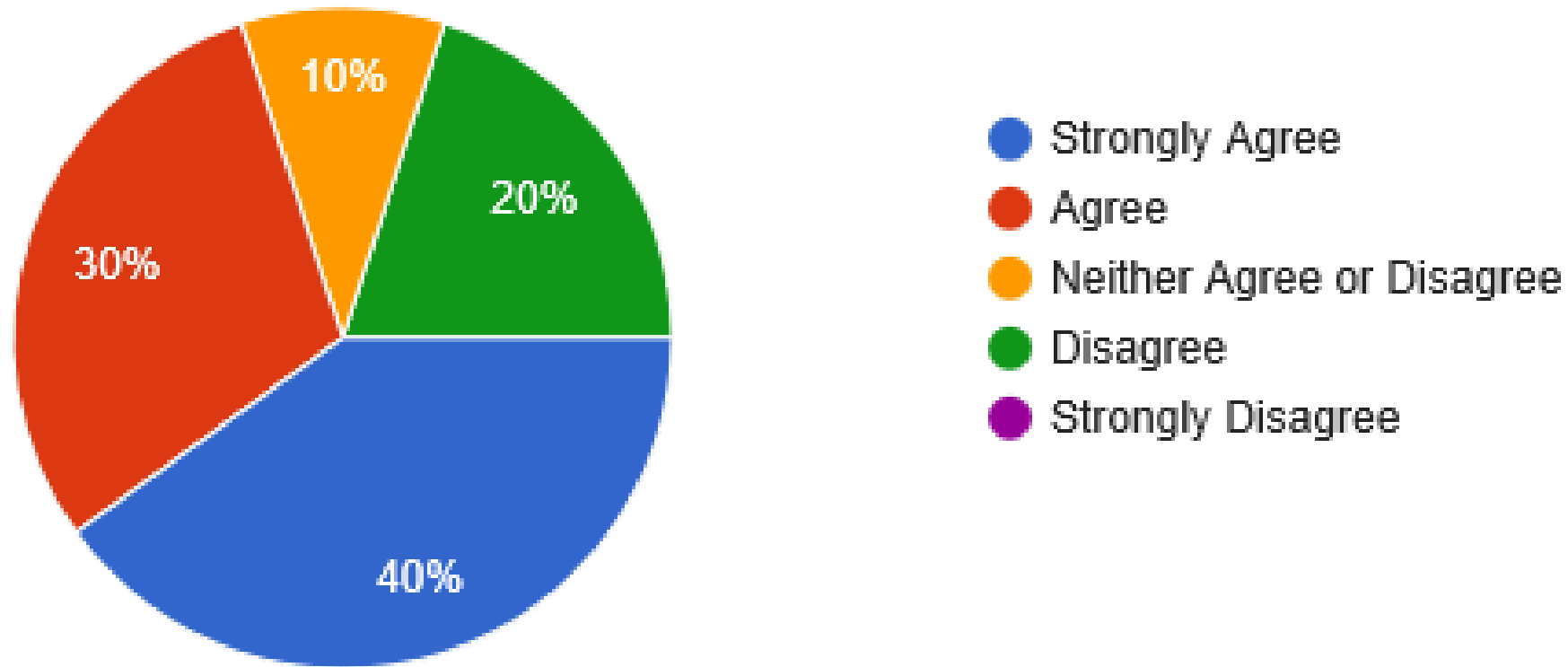
- We questioned parents of children with epilepsy
- Children aged 2-12y
- 60% Male – 40% Female
- Covering many different seizure types
  - Absent / Focal / Generalised / Grand-Mal

# New Passport: Questionnaire

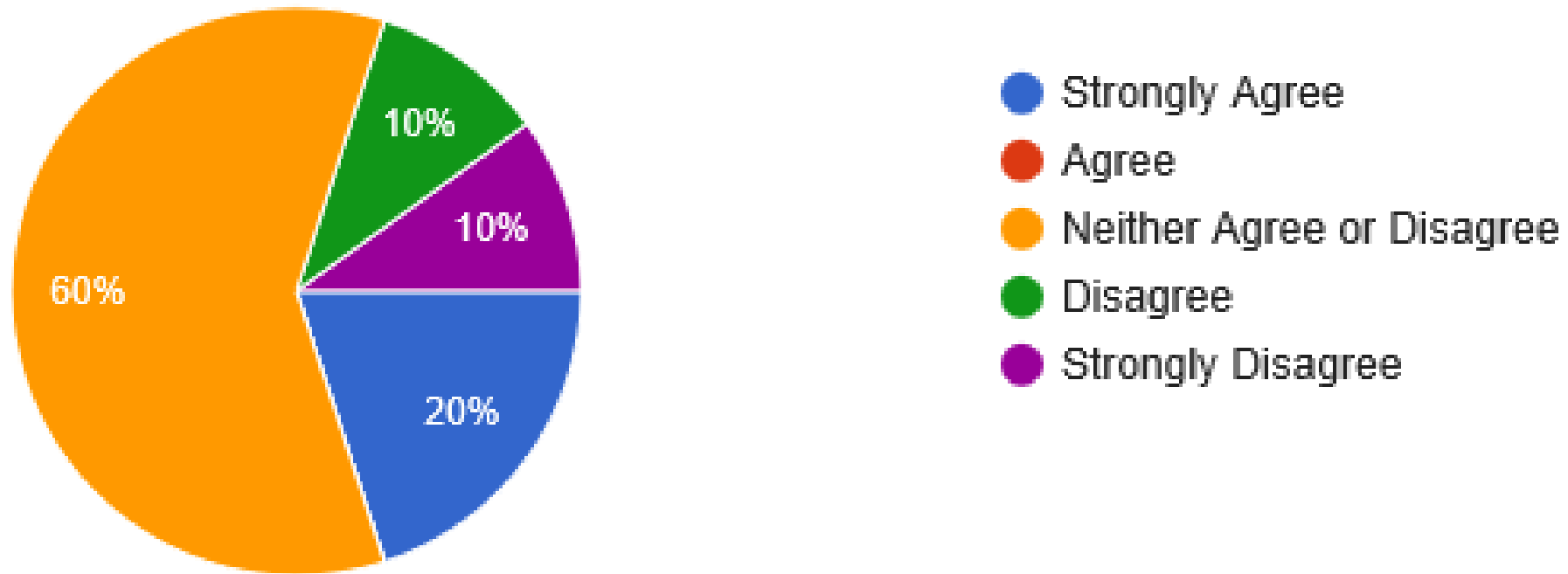
*Parents*

	High Impact	Low Impact
High Power	Consultant Pediatricians Epilepsy Nurses	Trust board CEO
Low Power	IT Department <b>Patients</b> <b>Parents</b>	Secretaries GPs Emergency Care Doctors Schools

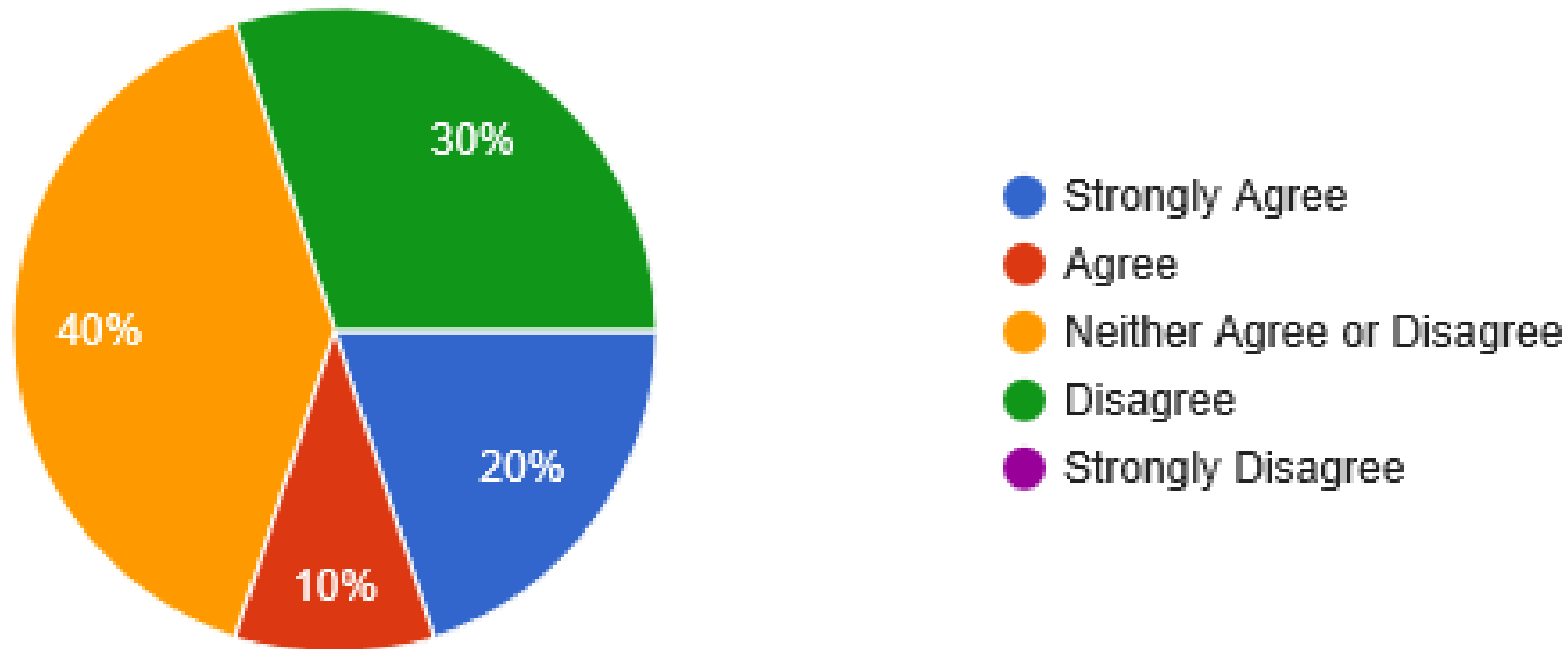
# Parents currently find the information to be useful to them



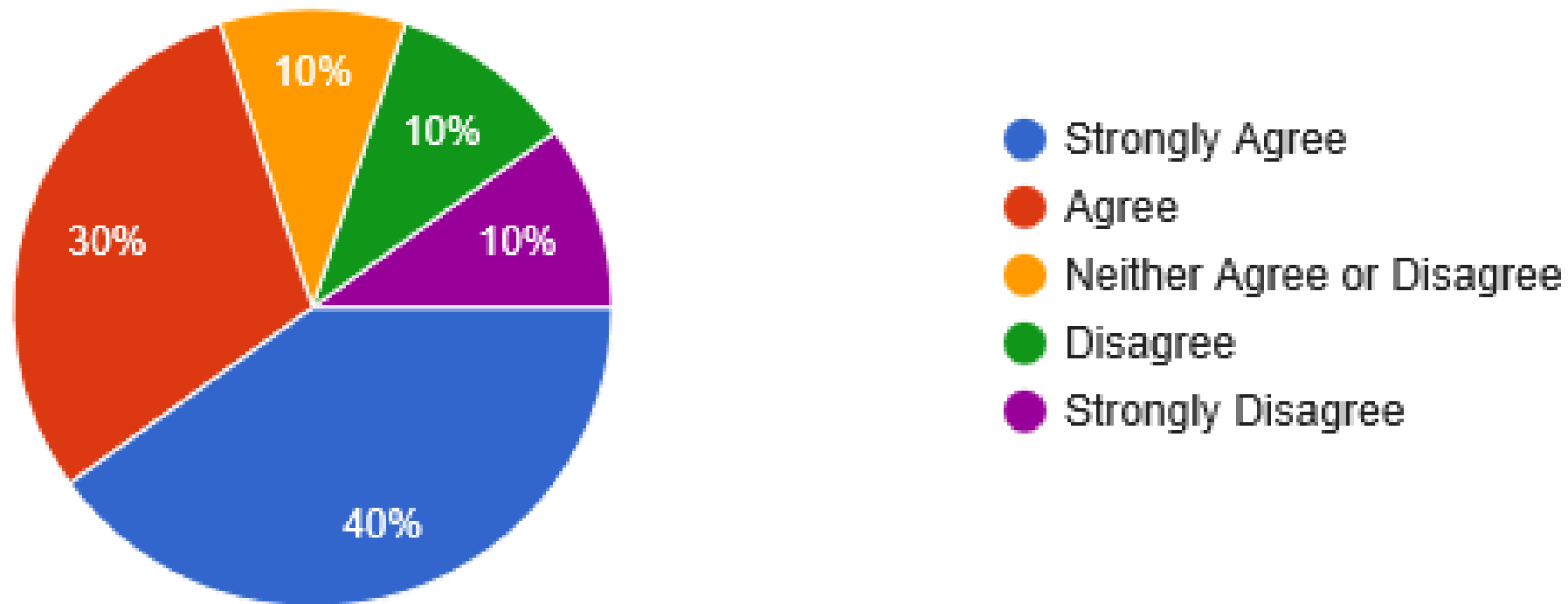
# Parents currently find the information to be useful to their child



# Parents currently find the information to be useful to schools and teachers



# Parents use the current information regularly



# Lots of separate pieces of information

- Parents don't know what information they have
- Information from lots of different sources
- No method of organisation
- **Some parents feel disengaged**



# PLAN

- Designing the passport
- Developing new patient pathway
- Response from stakeholders
  - Parents
  - GPs
  - Schools
  - Pediatricians
  - Epilepsy nurses

## PLAN

Project Initiation Document (PID) (PM)

Business Case (PM)

Project Charter (PM Level 2)

Action Plan (PM Level 2)

Project Plan (PM)

Communications Plan or in PID (PM)

Managing Risks and Issues

Risk Register (PM)

Issues Register (PM)

DOSE  
for Improvement  
Control (SPC)



# Passport Design

## EPILEPSY PASSPORT - DRAFT

NAME:			
DOB:	/	/	NHS Number
EMERGENCY CONTACT	Name: Phone Number:		

EMERGENCY - I HAVE EPILEPSY. My seizures look like this:

If I have seizure please time the seizure and if it lasts for more than \_\_\_\_\_ minutes please:

- 
- 
- 



My rescue medication is:

Please note, if any changes are made please write these on the primary caregiver's hardcopy to be brought to the next clinic review and changed electronically.  
Latest clinic letter can be found on back page.

PERSONAL AND BACKGROUND INFORMATION			
HEIGHT (cm)		WEIGHT (kg)	
SEIZURE TYPE(S)			
EPILEPSY SYNDROMES			
CAUSE OF THE EPILEPSY			

Any additional co-morbidities or diagnoses

Current anti-epileptic medication(s) and dose(s)

Current other regular medications

Previous anti-epileptic medications and reason for stopping e.g. serious side effects/didn't work

Medication	Dose	Reason for stopping

Any allergies

Any previous epilepsy surgery? If so, provide details

Epilepsy passport completed by:

PRINT:	Date:
SIGN:	

Staff involved in care:

Name	Role	Hospital	Contact

CLINIC LETTER

Seen by:

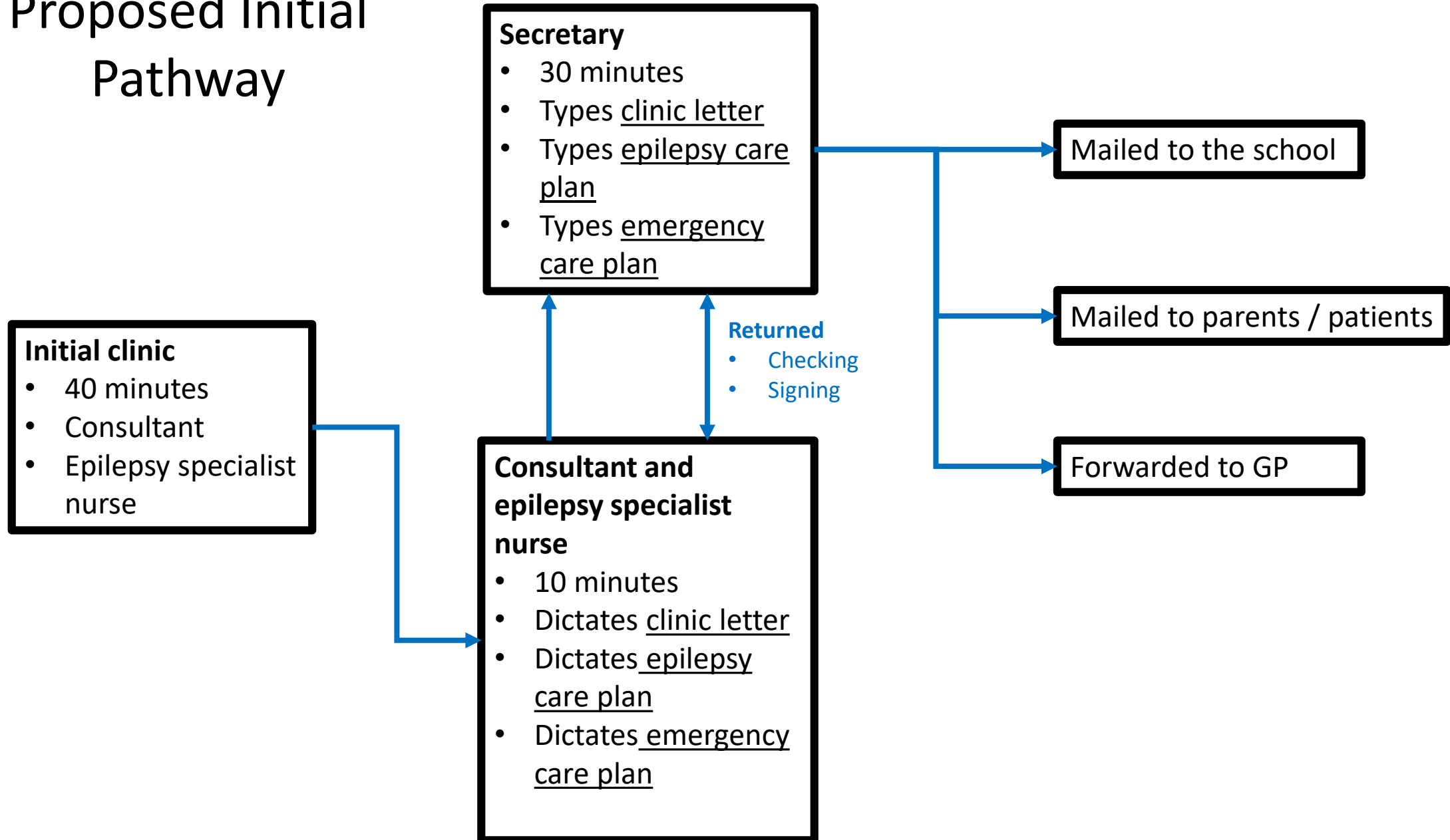
Date:

Information:

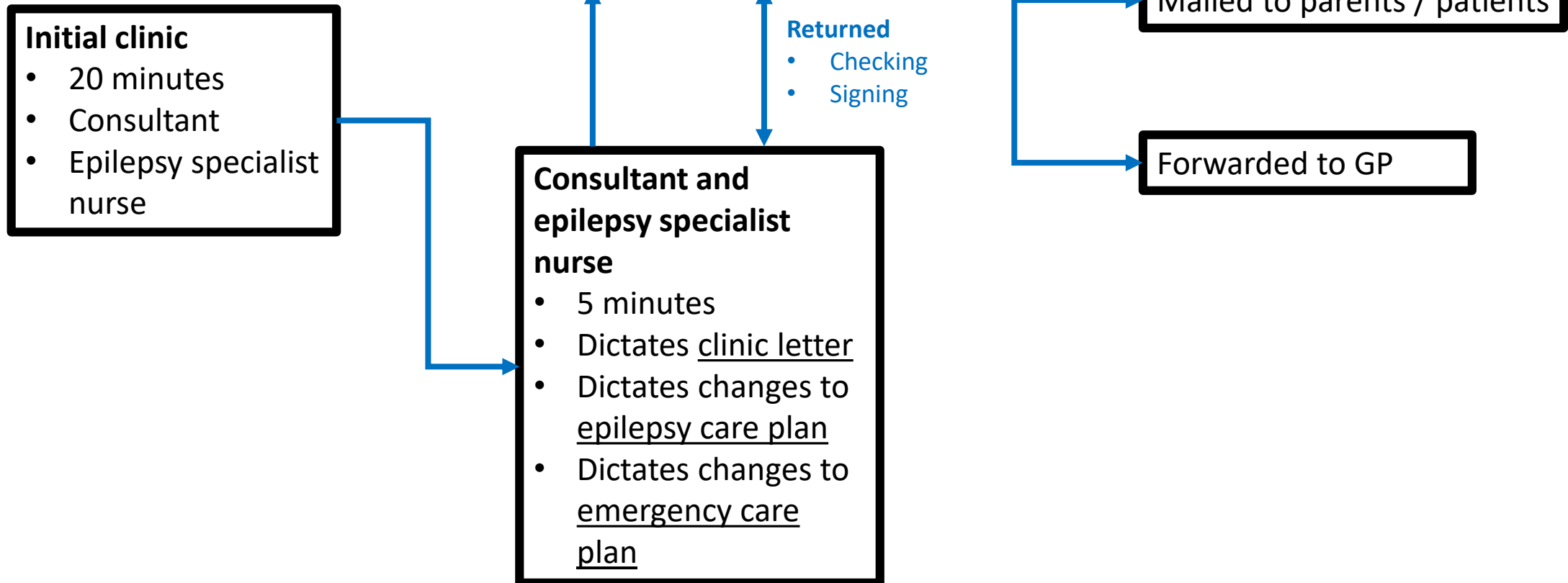
# Modified Passport

- Clinic letter at the front – for GPs
- Separate page for emergency care plan
- Re-order height and weight

# Proposed Initial Pathway



# Proposed Review Pathway



# Proposed Cost and Savings

- £66.24 per initial consultation
- £33.12 per review consultation
- Estimated saving of £203.45 per clinic
- Reduced administration work by epilepsy specialist nurses
- Administration work typed by secretaries

# Finance Summary

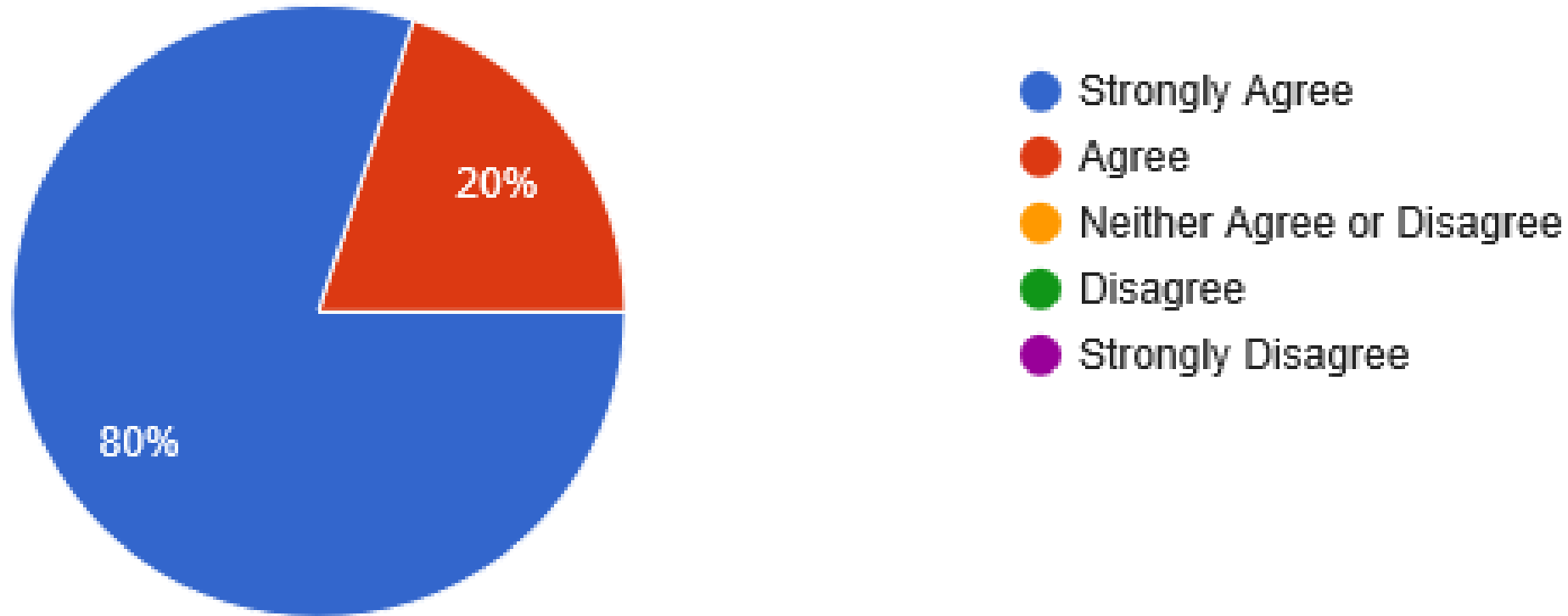
## Key costs:

- Epilepsy passport for all current patients
- Setting up an IT system for the epilepsy passport
- Estimated saving of £46,793.50 over 5 years
  - 300 current epilepsy patients
  - £30,627
- System development cost
  - Unknown

# Improvement: Questionnaire

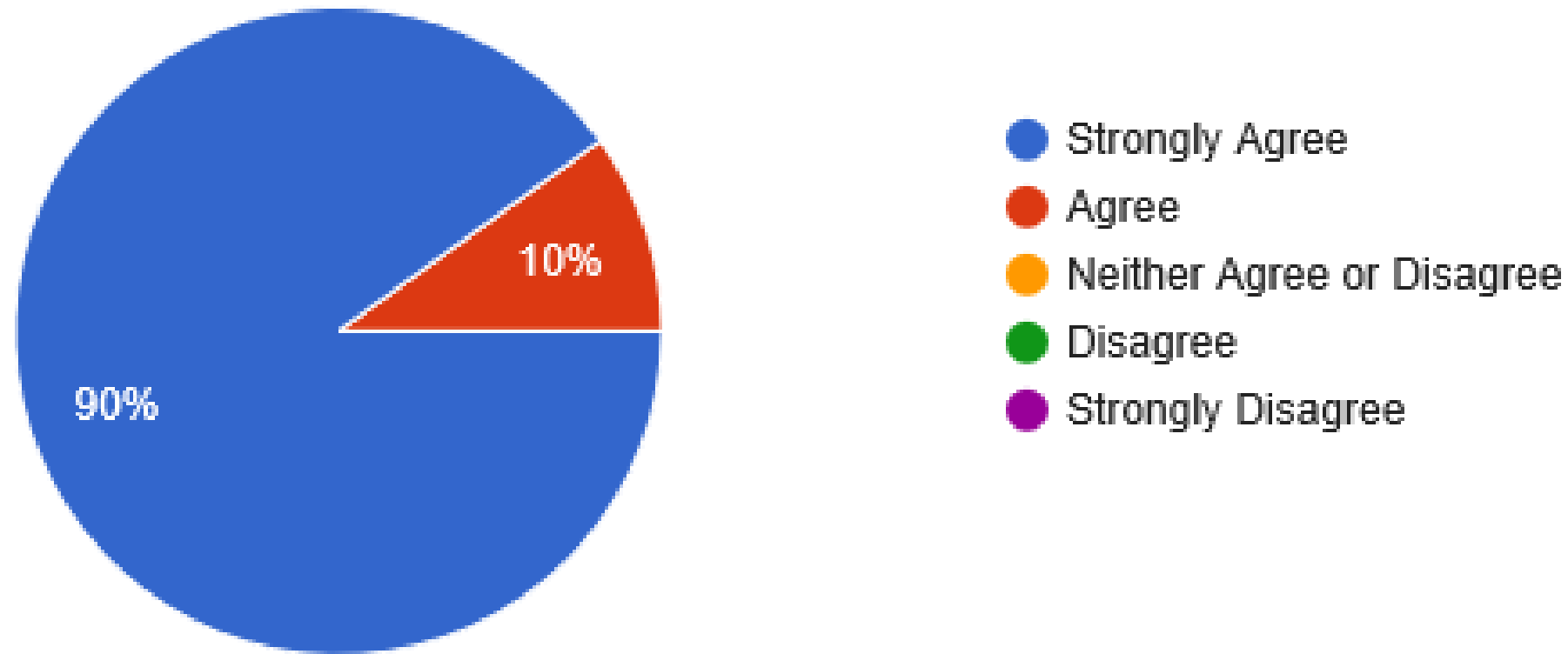
- We questioned parents of children with epilepsy
- Children aged 2-12y
- 60% Male – 40% Female
- Covering many different seizure types
  - Absent / Focal / Generalised / Grand-Mal

# Parents think the new passport will be useful to them

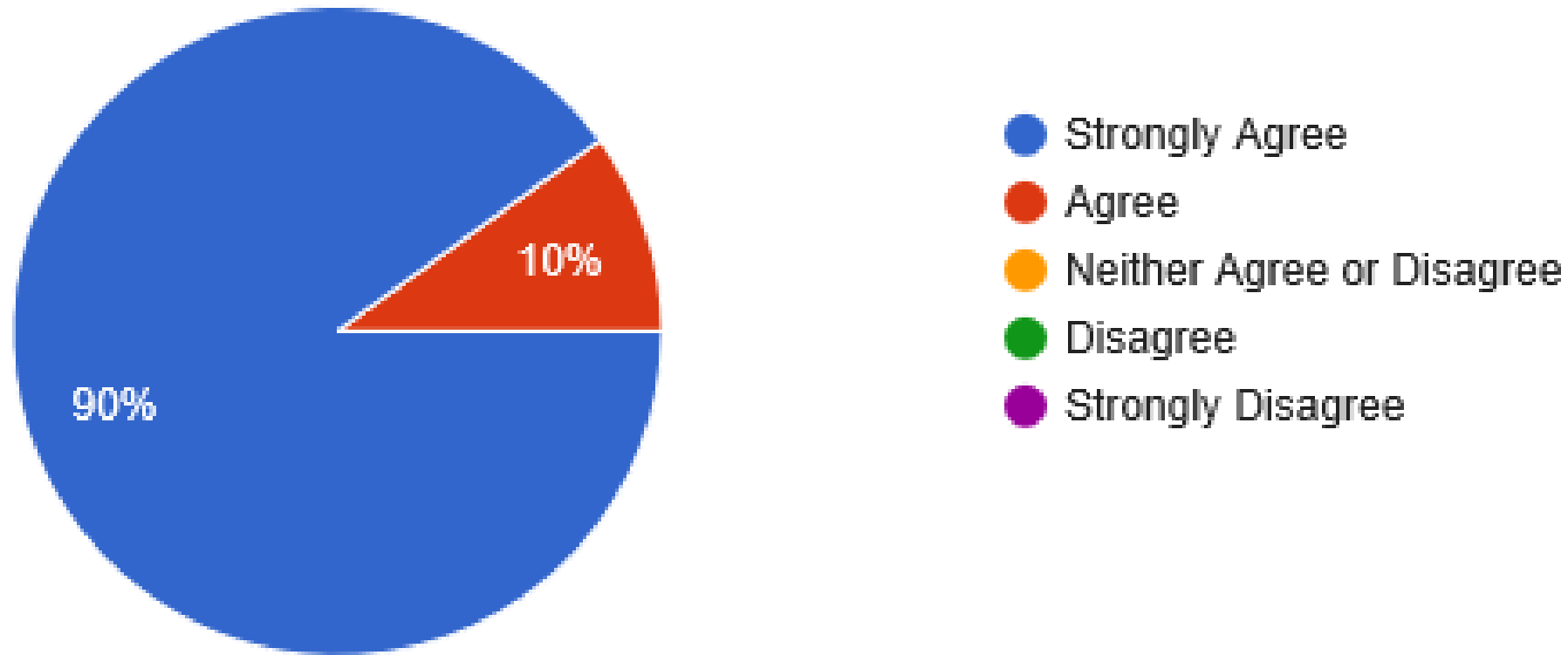




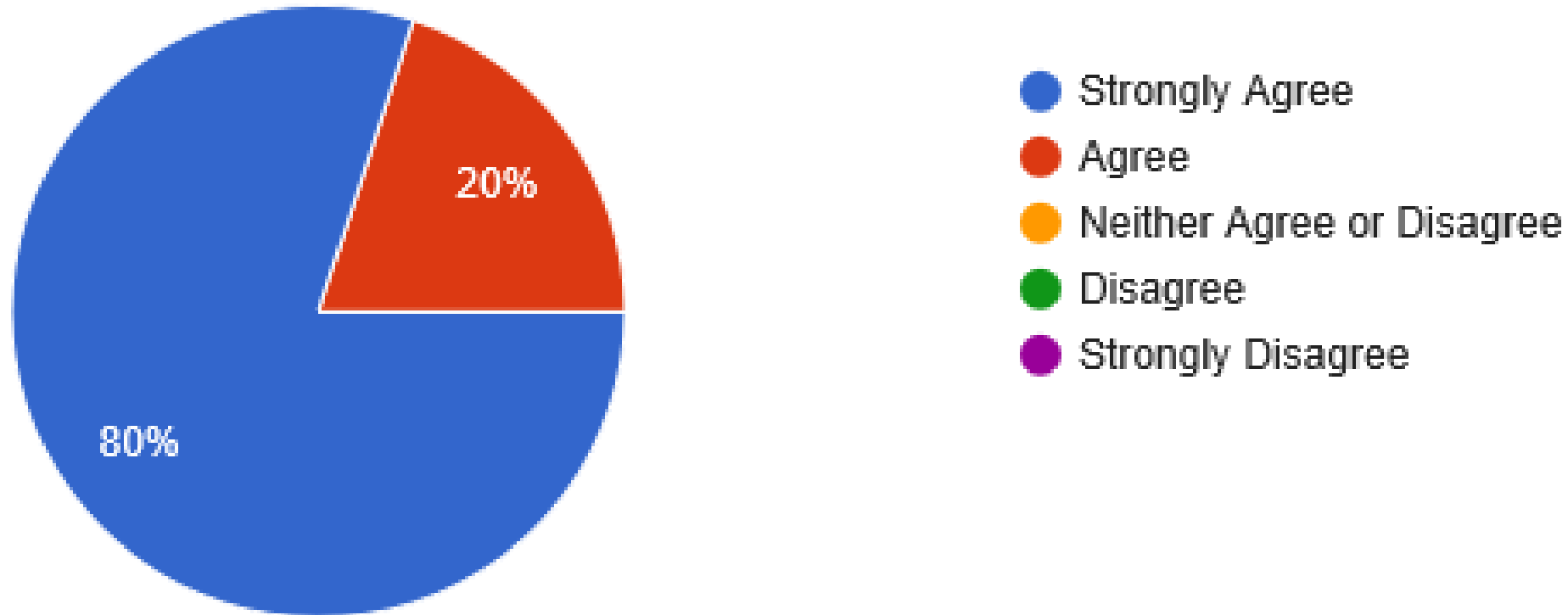
# Parents think the new passport will be useful to their child



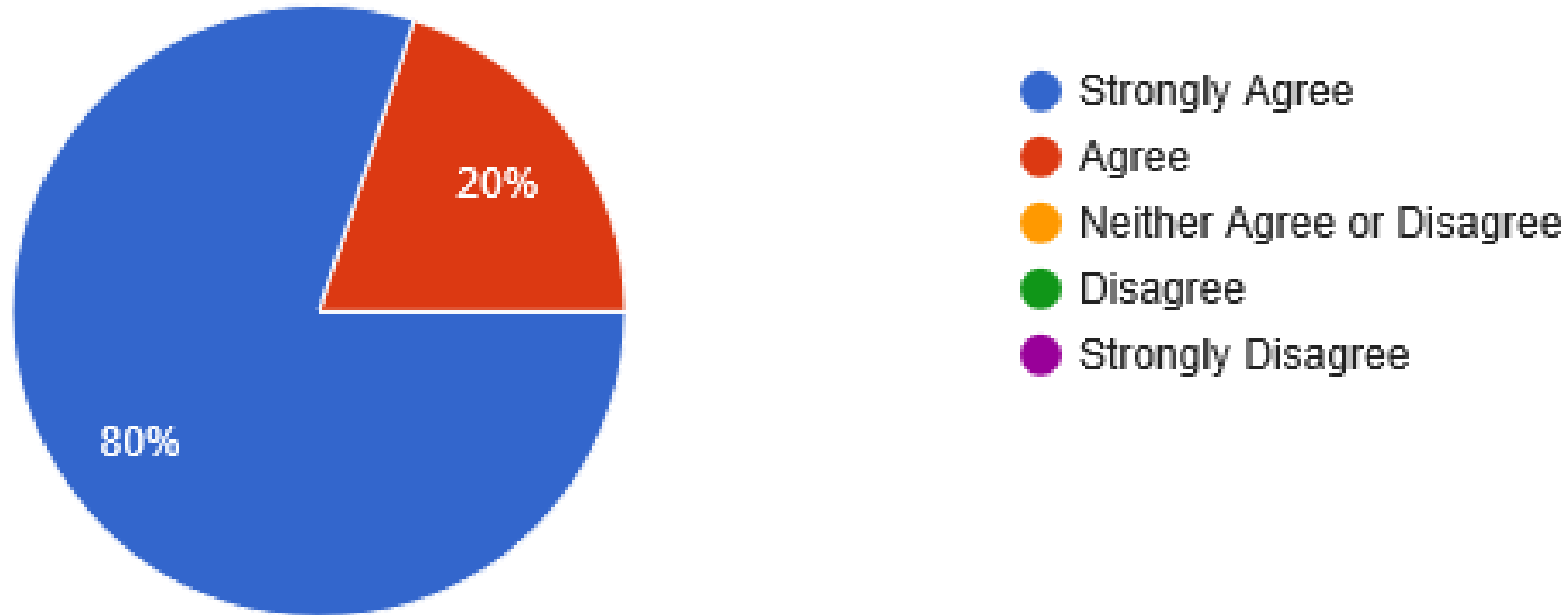
# Parents think the new passport will be useful for schools and teachers



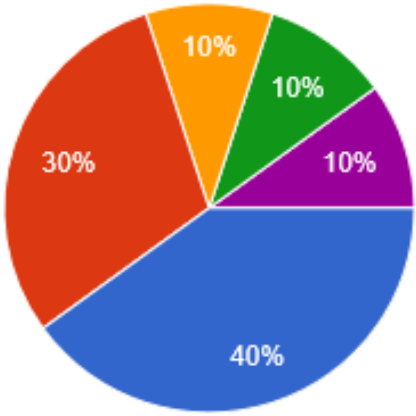
# Parents think they would use the epilepsy passport more often



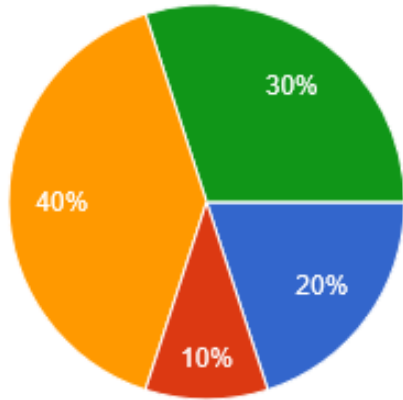
# Parents thought the Epilepsy Passport is an improvement on current information



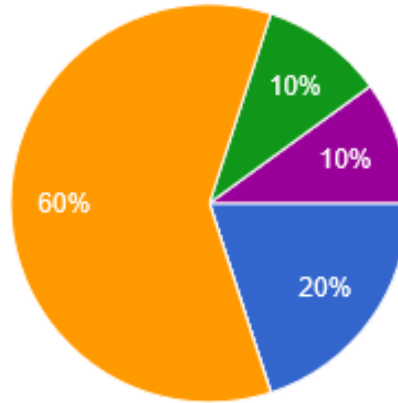
# Comparison



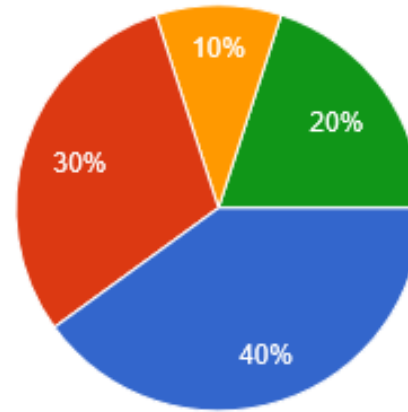
Personally



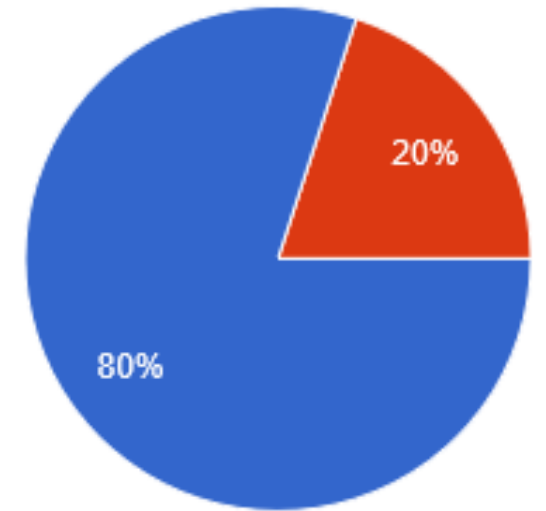
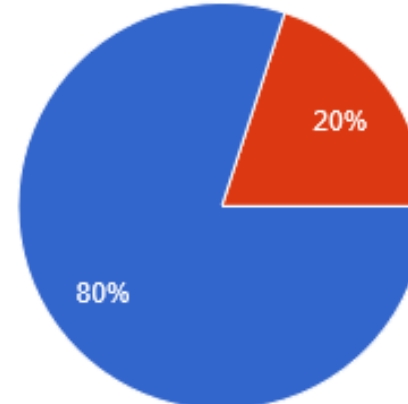
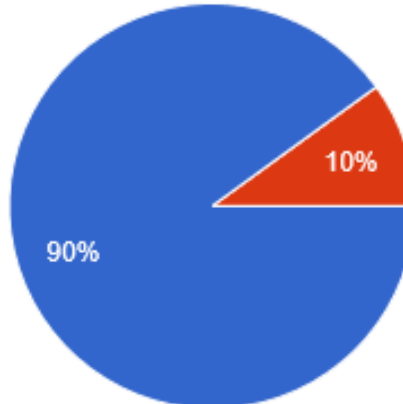
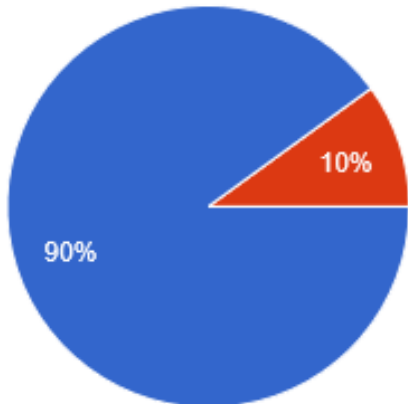
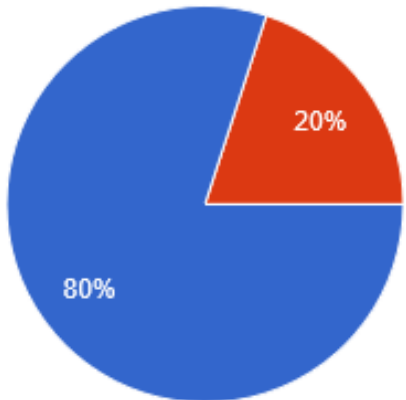
Child



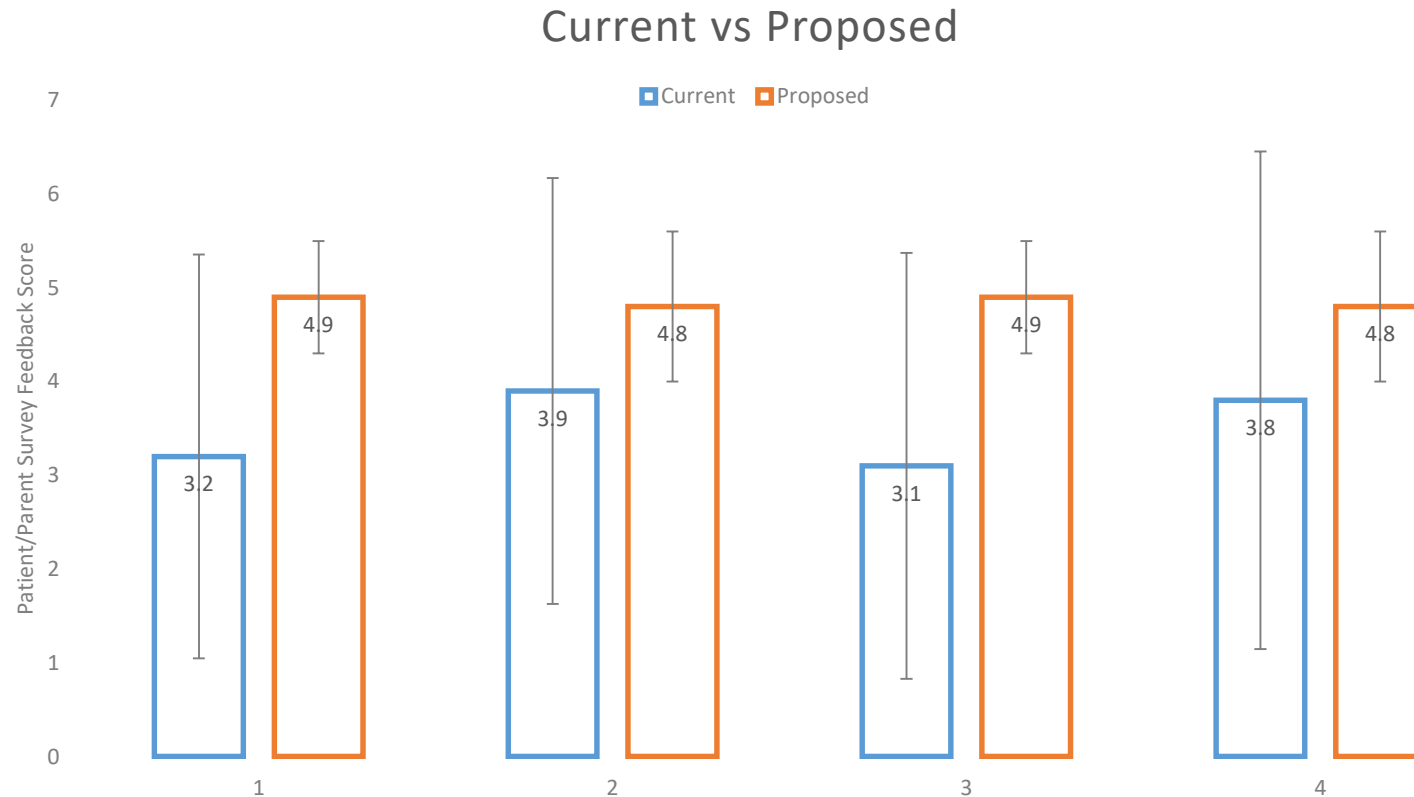
Teacher



Usability



# Comparison: Current vs Proposed Results



- Current **3.2** (95% CI 1.05 – 5.35,  $p < 0.05$ ) vs Proposed **4.9** (95% CI 4.30 – 5.50,  $p < 0.05$ )
- Current **3.9** (95% CI 1.63 – 6.17,  $p < 0.05$ ) vs Proposed **4.8** (95% CI 4.00 – 5.60,  $p < 0.05$ )
- Current **3.1** (95% CI 0.83 – 5.37,  $p < 0.05$ ) vs Proposed **4.9** (95% CI 4.30 – 5.50,  $p < 0.05$ )
- Current **3.8** (95% CI 1.15 – 6.45,  $p < 0.05$ ) vs Proposed **4.8** (95% CI 4.00 – 5.60,  $p < 0.05$ )

# What parents liked about the epilepsy passport:

- “Easier to pass information on to relevant people”
- “All of the information in one place”
- “Saves having to write up information about my child repeatedly”
- “Information for schools in a condensed way”
- “All of it!”
- “Informs people about seizures rather than having to tell everyone”

# What parents wanted adding:

- “Anything the child may not be able to do because of epilepsy – schools often ask for this”
- “Digital copy that could be emailed”
- “Addition of a seizure diary” – this was a common theme
- Addition of information boxes regarding seizures



# New Passport: Stakeholder Involvement

	High Impact	Low Impact
High Power	Consultant Pediatricians Epilepsy Nurses	Trust board CEO
Low Power	IT Department Patients Parents	Secretaries GPs Emergency Care Doctors Schools

# REDESIGN

- First Redesign
  - Informal discussion with ESN and consultants
- Second Redesign
  - Formal information gathering
  - Parents / GPs / Consultants / ESNs
- Current Draft
  - See handout

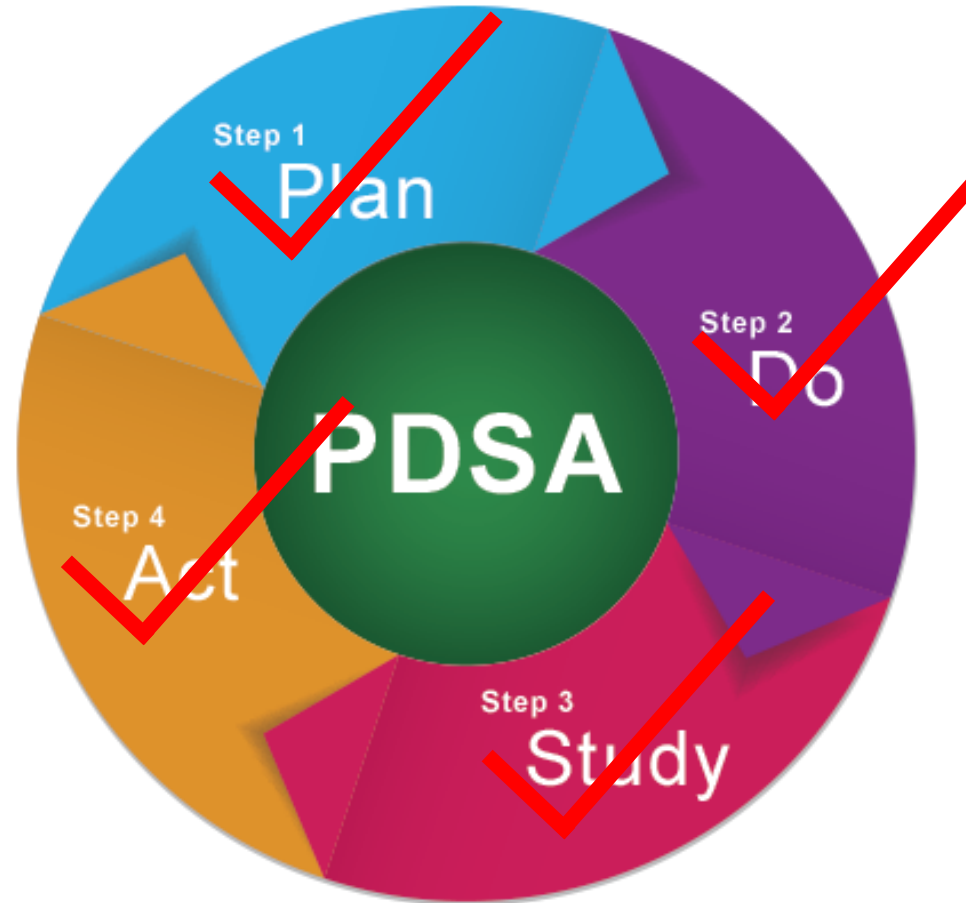
## REDESIGN

Ice Breakers  
Creative Problem Solving  
Educate  
Workforce Redesign  
Presentation Skills  
Ease and Impact  
Lean Thinking  
Clinical Microsystems

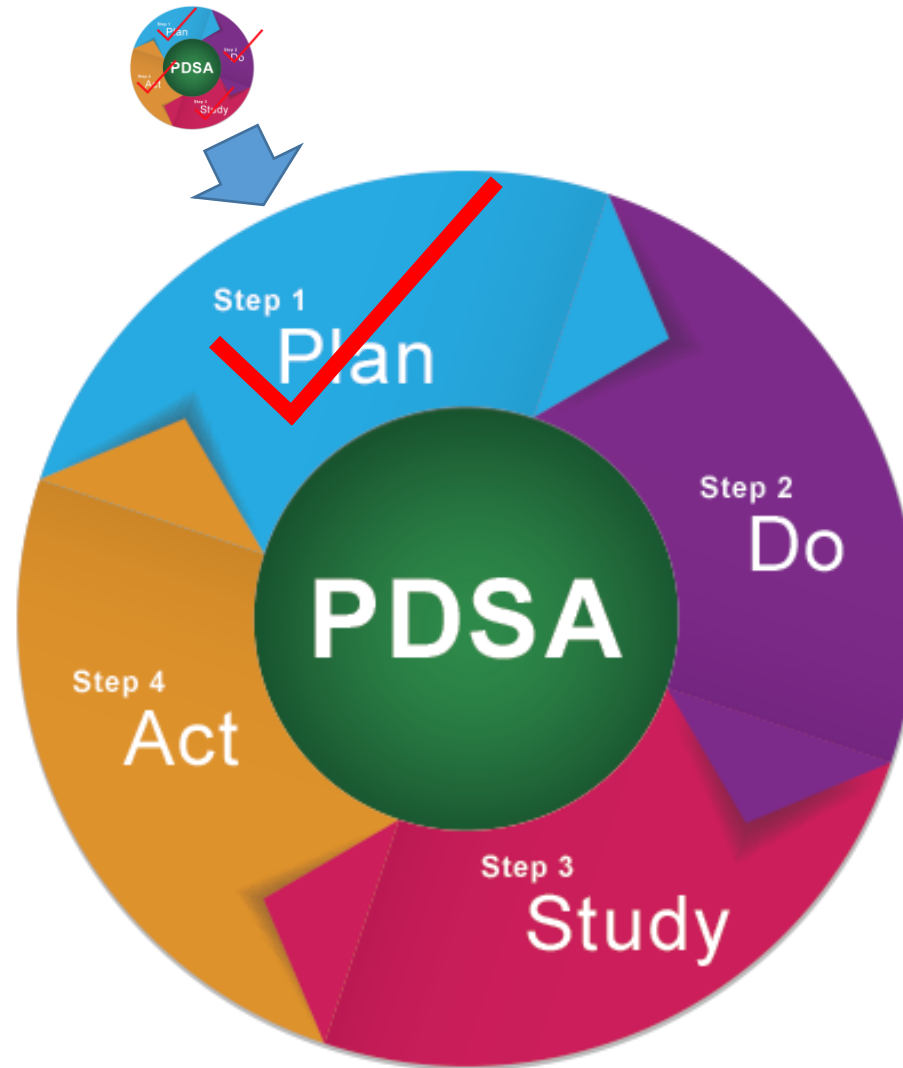
# Final Draft

- A personal space for parents – *parent request*
- Check box for verbal information given – *consultant request*
- Useful seizure first aid and emergency identification – *parent request*
- Patient limitation box – *parent request*
- Fine adjustments to structure – *consultant and ESN requests*

# PDSA Cycle - 1



# PDSA Cycle 2



# TRIAL

- Not at the point of trial yet
- IT is the main stumbling block
  - Currently attempting to address these issues
  - Once resolved will start trial
- Future assessment of implementation

## TRIAL

Measurement for Improvement

Wheel of Multiple Perspectives

PDSA Cycle

SPC

Leadership

Workstream Update Report (PM)

Risk Register (PM)

Issues Register (PM)

Sustainability Diagnostic Tool

# Summary

- Meets NICE and RCPCH recommendations
- Improvement in patient care (theoretically until trialed and proven)
- Financially beneficial

# References

[1] Nice.org.uk. (2012). *Epilepsies: diagnosis and management / Guidance and guidelines / NICE*. [online] Available at: <https://www.nice.org.uk/guidance/cg137> [Accessed 20 Apr. 2016].

[2] Rcpch.ac.uk. (2016). *Epilepsy Passport / RCPCH*. [online] Available at: <http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/epilepsy-passport/epilepsy-passport> [Accessed 20 Apr. 2016].



Any Questions?

