

Medicines Optimisation in Special Schools



Reporter/ Project Lead: Nirusha Govender, Lead Pharmacist Children, Young People and Dental Services

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GLOSSARY:

CYP – Children and Young People

SEND - Special Education Needs or Disability

NASEN – National Association for Special Education Needs

EHC – Education, Health and Care Plan

PRU – Pupil Referral Units

KCHFT – Kent Community Health NHS Foundation Trust

HEE - Health Education England

ADHD – Attention Deficit Hyperactivity Disorder

STOMP - Stopping The Over-Medication of Adults and CYP with a learning disability, autism or both

STAMP - Supporting Treatment and Appropriate Medication in Paediatrics

LVS – Local Vaccination Service (COVID Vaccination Programme)

TEAM:

Project Lead: Nirusha Govender, Lead Pharmacist for Children, Young People (CYP) and Dental Services

Accountable Officer: Dr Ruth Brown, Chief Pharmacist

CYP Pharmacy Team:

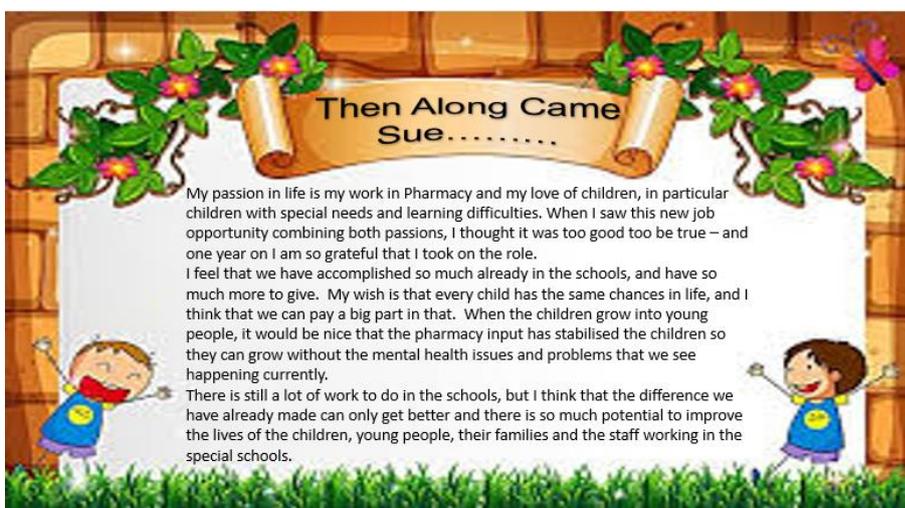
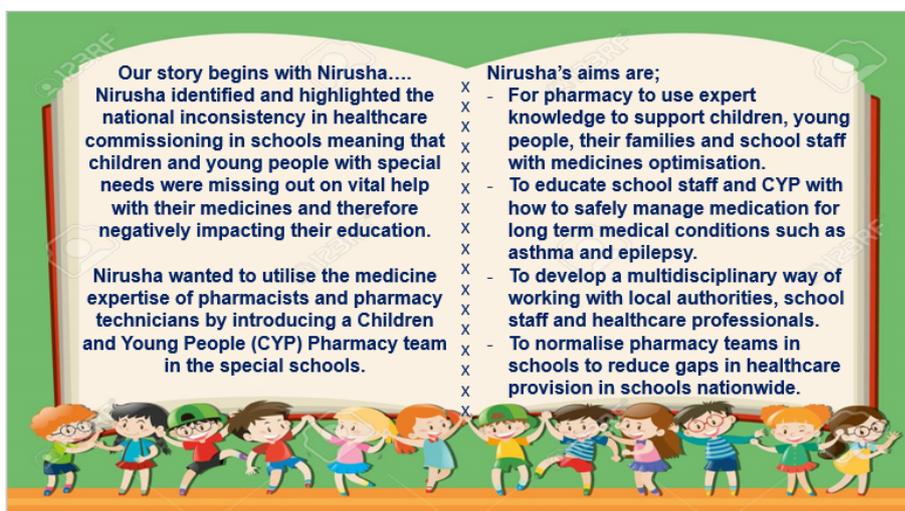
Vanessa Lawrence, Advanced Pharmacist

Susan Goss, Specialist Pharmacy Technician

Sarah Owen, Specialist Pharmacy Technician

Chantelle Hay, Specialist Pharmacy Technician (HEE funded transformation project post)

The team are all passionate and committed to addressing the health inequalities and improving access to medicines optimisation in special schools. In order to get a real understanding of who they are, here are some brief introductory tiles to people behind the results of this project.

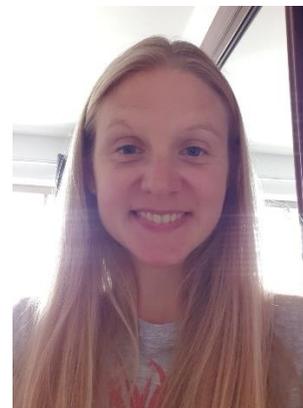


Then Along Came Sarah.....

As soon as I saw the application for the CYP team I was instantly attracted to it. For me, the appeal was something new in pharmacy that I had not had any experience in, but it was more than that. There was just something that made me convinced I needed to go for the position.

Well, I was lucky enough to have been employed in the role and almost one year on it is a decision I do not regret in the slightest. I am part of a small but fantastic team and we all work well together and share the same hunger and desire for making changes concerning medication within the special school setting. I have learnt that it is a building process, that in order to have a real impact within the special schools that we cover it is something that is going to take time, but I feel proud and privileged to be here at the very start of it all.

I am so excited by the impact we could potentially have and truly see this as benchmarking work that will guide and set standards for other Trusts and areas of the country to follow.



Then along came Vanessa.....

I was attracted to this role because it appeared to be an untapped area of pharmacy that interested me. Nearly a year has passed and I am privileged to be involved with such pioneering work. As we are aware, there is currently a huge disparity in the health and education that children receive nationally, in particular those with special educational needs and disability (SEND). Children and young people are our future, therefore it is important that we invest time and resources in their health and well-being. Pharmacy involvement in schools will allow for early interventions for children and young people, which will improve health outcomes. To add pharmacists will be able to deprescribe and regularly reviewing medication. Furthermore by having pharmacist and pharmacy technicians input in special schools, we can establish good medicine practices and where possible equip children, young people and their families with the tools to better manage their condition and medicines in the future.



Then along came Chantelle.....

After coming across the job vacancy for this post, I just knew it had to be mine! After some long hard thought, I decided to bite the bullet and apply for the position. I didn't think in a million years I would get the job, but when I was invited for an interview I couldn't believe, that this job that sounded so right for me was a step closer to becoming mine!

After the interview I thought I had tried my best and if it is meant to be, I will get the position. Well, when I got the phone call to say I had been successful, I honestly could of cried and couldn't believe my luck!

After over a decade of working within the community pharmacy it felt like it was my time to shine and move out into such an innovative sector of pharmacy. I am hugely passionate about my job and absolutely love that I have the pleasure and opportunity to work with such amazing people and children, where you really do feel like you are helping to change lives. Everyday is such a delight to come to work and I have never felt like that about a job, so it really is something special!

I can't wait to watch this work grow, and truly believe amazing things WILL be achieved in such a unique service.



BACKGROUND:

The number of dispensed prescriptions for children and young people (CYP) has increased in recent years¹ and an increasing number of CYP need to take medicines during school time for a range of medical conditions including asthma, epilepsy, diabetes and attention deficit hyperactivity disorder (ADHD).

“Special schools are those that provide an education for CYP with a special educational need or disability (SEND). There are many different types of special schools, but essentially, they all educate CYP whose needs cannot be met within a mainstream setting, and whose parents or carers have agreed to or requested a special school placement”, as explained by Alex Grady, Education Development Officer at the National Association of Special Educational Needs (NASEN)².

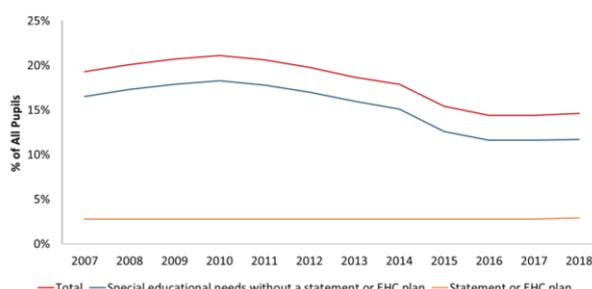
There are 1,033 state-funded and non-maintained special schools in England. The approved type is according to the special need for which the school is formally approved to make provisions for. Autistic Spectrum Disorder is most common, with 673 state-funded and non-maintained special schools and other types include:

- 551 schools for Severe Learning Difficulty
- 533 schools for Moderate Learning Difficulty²⁻⁴.

The percentage of pupils with a statement or Education, Health and Care (EHC) plan attending state-funded special schools has seen a year on year increase since January 2010 from 38.2% to 44.2% in January 2018³. Approximately 2% of school-age CYP attends a special school, and the vast majority have a statement or EHC plan.

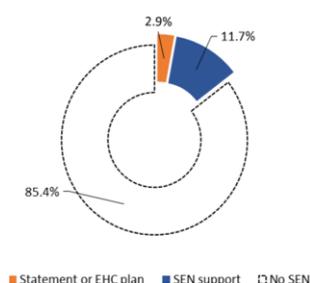
The Department of Education published graphical statistics for SEND schools which illustrates this steady rise in the figures³ below:

The percentage of pupils with special educational needs has increased to 14.6%...



The number of pupils with special educational needs (SEN) has increased for a second consecutive year from 1,244,255 in January 2017 to 1,276,215 in January 2018, an increase from 14.4% to 14.6% of pupils.

...and the percentage of pupils with a statement or EHC plan has increased to 2.9%



253,680 pupils have a statement of SEN or an Education, Health and Care (EHC) plan. This is an increase of 11,495 since January 2017, from 2.8% of the total pupil population to 2.9%.

A further 1,022,535 pupils are on SEN support. This is equal to 11.7% of the total pupil population, an increase from 11.6% in January 2017.

Why is this an issue for special schools?

On 1st September 2014, a new duty came into force for governing bodies to make arrangements to support pupils at school with medical conditions⁵. Section 100 of the Children and Families Act 2014⁶ places a duty on governing bodies of maintained schools, proprietors of academies and management committees of pupil referral units (PRUs) to have in place arrangements to support pupils with medical conditions at their school⁵.

Appropriate authorities must have regard to this guidance when carrying out their statutory duty to make arrangements to support pupils at school with medical conditions. The guidance also applies to activities taking place off-site as part of normal educational activities⁵.

Key points in the guidance that require consideration by special schools include:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education.
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of CYP with medical conditions are properly understood and effectively supported.

Within the collaborative commissioning structure between the NHS and Local Authorities for special schools, there has never been a formal pathway to promote or support the need for a pharmacy led medicines optimisation service in schools. The SEND reforms introduced by the Children and Families Act 2014⁶ focus on two key themes: greater co-operation between education, health and social care and a greater focus on the outcomes. The Act, along with the comprehensive guidance in the SEND Code of Practice: 0-25 years (July 2014)⁷, outlines detailed requirements for the planning and delivery of services to this important group of CYP. They also require local authorities to implement joint commissioning arrangements with their Health partners for the education, health and care of CYP.

With there being no standardised approach to how this is achieved, great variations exists nationally on how this model is being delivered; including vast differences even in localised areas where some schools have full collaborative working between local authorities and health partners (primarily specialist community nursing services) and other schools having little or no support at all with the need to fund their own health provisions.

What are the challenges in special schools?

CYP attending special schools have recognised physical and/or mental health conditions, with many having complex health and care needs. This includes requiring administration of medicines (sometimes off-label or unlicensed) with complex dosing regimens in specific conditions/managing acute episodes, and also include medicines administered via specialist devices e.g. intrathecal pumps, enteral feeding tubes, infusion pumps and syringe drivers.

It is not a requirement for a special school to employ a school nurse, thus in the majority of special schools, teachers and teaching assistants play a significant role in medicines administration, storage and other healthcare related matters during school hours. In most cases these individuals lack medical or pharmaceutical experience. Parents can worry when sending their child to school, if medicines are needed during the school day and there can also be anxiety for staff if they do not feel confident in administering it.

The growing evidence⁸⁻¹⁰ highlights an important need to get the fundamentals of medicines use right for CYP in schools.

A cross-sectional survey of schools undertaken in 2017 by Bellis et al¹¹ identified that there were vast differences between how individual schools managed medicines and interpreted policy guidance and also discrepancies between the views of CYP, parents, schools and healthcare professionals. The study highlighted that there is some evidence that medicines management provisions do not always meet the needs of CYP and their families with fewer than half of parents and healthcare professional being satisfied with how medicines are dealt with in schools. This is similar and even more challenging for special schools with a strong emerging evidence base¹²⁻¹⁵ highlighting the complexity of medical conditions and the nature of medicine regimens administered in schools. McCarthy et al¹⁴ recommended that consultation with a pharmacist may provide valuable advice on storage and accurate dispensing of medication.

Examples of medical conditions requiring management in special schools as outlined by Aruda et al¹⁵ include:

TABLE 2. Type of Health Problem Reported by Parents

Body System	Frequency	Diagnoses Listed
Chromosomal anomalies	5	Cornelia de Lange, congenital hydrocephalus, Rett syndrome, and neurofibromatosis
Gastrointestinal disorders	10	Gastro esophageal reflux, oromotor dysfunction requiring gastrostomy tube dependence, and disorders of gastric motility
Neurodevelopmental disorders	19	Ranging from simple developmental delay to global developmental delay, pervasive developmental disorder, and autism
Psychiatric disorder	1	Panic disorder
Brain disorders	5	Hypoxic ischemic encephalopathy, cerebral vascular insult, closed brain injury, and hydrocephalus
Vision impairment	5	Retinopathy of prematurity and cortical blindness
Seizure disorder	13	None specified
Genitourinary disorders	4	Neurogenic bladder, vesico-ureteral reflux, and recurrent urinary tract infection
Nephrology disorders	2	Renal stones and chronic renal insufficiency
Communication impairment	7	None specified
Neurosensory hearing loss	2	None specified
Pulmonary disorders	3	Asthma, chronic respiratory failure, and obstructive sleep apnea
Neuromuscular disorders	14	Cerebral palsy, spastic quadriplegia, hypotonia, and scoliosis
Unknown diagnosis	2	

AIMS AND OBJECTIVES:

Within the collaborative commissioning structure between the NHS and Local Authorities for special schools, there has never been a formal pathway to promote or support the need for a pharmacy led medicines optimisation service in special schools. Hence, huge variations exist nationally on how this model is being delivered. Community health services play a key role in the future of health and care systems. This project not only meets HEE business priorities but also the NHS long term plan through service transformation and redesign in the following areas:

- Pharmacy workforce development
- Advanced Practice
- Mental Health
- Learning disabilities and Autism.

Project Aim:

The primary aim of this project will be to promote:

1. Increased patient safety in schools through the development of a bespoke medicines optimisation service that allows for the:
 - 1.1 Improvements to upskill unregistered teaching workforce in medicines administration
 - 1.2 Reduction in Errors – e.g. omitted doses through medicines reconciliation provision
2. Standardisation, consistency and equality of health provision across more special schools in Kent through recruitment of an additional Pharmacy Technician to complement the new service
3. Development and transformational leadership opportunities for Pharmacy technicians expanding on their traditional roles through working in a relatively untapped sector i.e. special schools promoting medicines optimisation.

Project Objectives:

The key medicines optimisation objectives of a specialist pharmacy service within special schools will:

- Support safe and effective management of medicines to children in school
- Support seamless transfer to adopting the new medicines management training, governance, audit and overall quality improvement package
- Introduce an incident reporting and learning culture
- Promote access to the medicines information service
- Promote self-care to support the implementation of the March 2018 NHS England guidance to CCGs which prohibits routine prescribing for OTC medicines
- Increase awareness and understanding of the recent protocols for emergency use of salbutamol inhalers with appropriate spacer devices, and adrenaline auto-injector devices.

Outputs:

There are differences between how individual special schools manage medicines and interpret policy guidance and discrepancies exist between the views of each stakeholder group. A specialist pharmacy service provision would support special schools in achieving the commissioned contract requirements through the implementation and promotion of fundamental medicines optimisation principles. The outputs from this project is expected to:

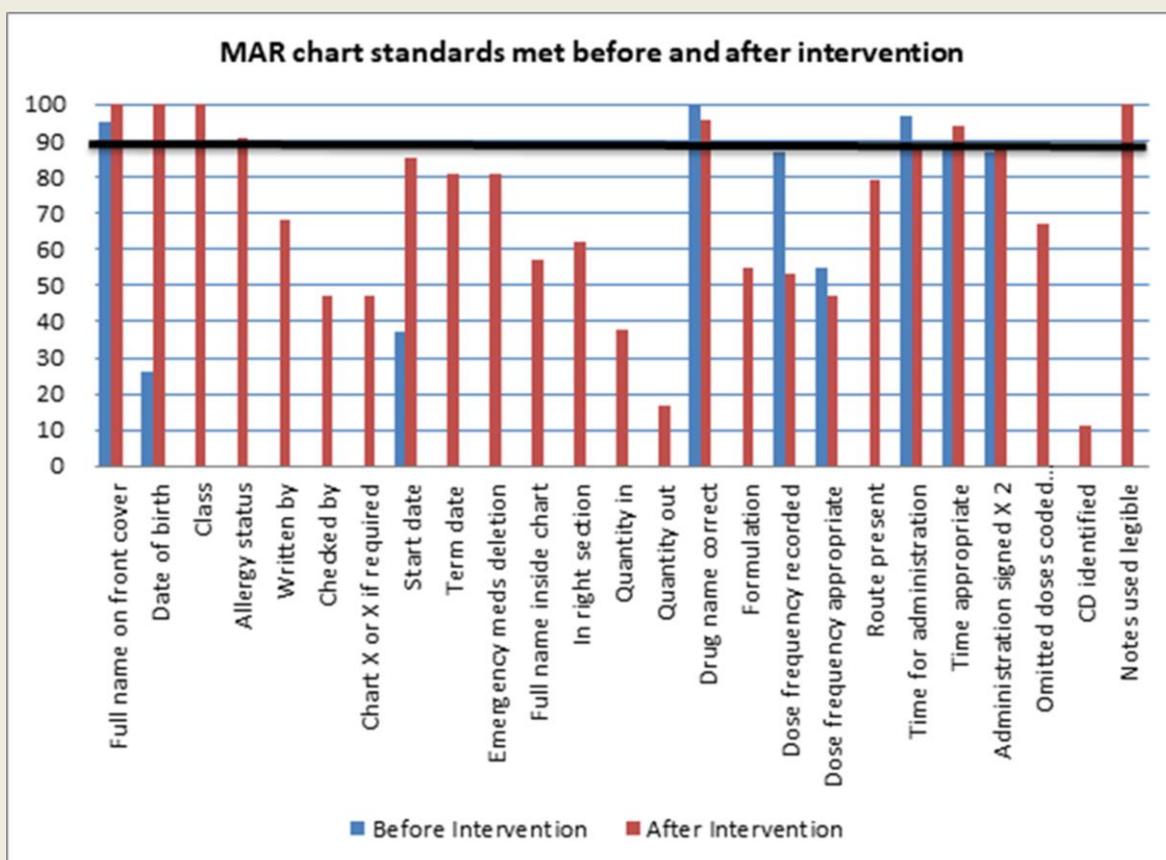
- Support the safe and effective use of medicines
- Improve patient safety in schools through access to a specialist medicines optimisation service
- Promote equity and equality in access to healthcare provisions within special schools for all children and young people with long term conditions.

METHODOLOGY:

Ideas and tests of change:

An earlier pilot study in 2018 by Kent Community Health NHS Foundation Trust (KCHFT)^{12,13} CYP pharmacy team in a special school highlighted that with the appropriate level of specialist pharmacy support the school were largely successful at supporting the safe and effective management of medicines to CYP minimising the risk of errors. Evidence illustrated in the figure below shows that standards¹⁴ on MAR charts increased from 9 out of 25 before the intervention to 25 out of 25 after the intervention. However, the number being met at 90% or above only increased from 3 to 7¹⁴, which emphasised the importance and need for ongoing collaboration between specialist pharmacy services and special schools.

Medway School of Pharmacy and KCHFT pilot study results: An Evaluation of Aspects of Medicines Management in a Special School in Kent.



The KCHFT CYP pharmacy team^{12,13} made appropriate interventions including deprescribing recommendations to the special school which directly supported the school to achieve a 60% reduction of when required (PRN) salbutamol inhalers at school, improving patient outcomes and indirectly minimised the medicines waste burden on the wider health economy.

A **Quality Improvement methodology** and approach was undertaken for this workforce transformation project using the following tools:

- Driver Diagram^{Appendix 1} to produce a strategy for implementation of the new service over a phased period of time during the academic year.
- PDSA cycle^{Appendix 2} to complete pre and post evaluation of medicines management practices as part of ongoing quality assurance monitoring.
- Logic Models^{Appendix 3} to supporting clarity in thinking which enabled the development of appropriate evaluation strategies throughout the project.

Kent and Medway Local Population Needs:

Special schools operate in Kent & Medway CCG to provide education services for CYP with high levels of disability, learning disability or special educational need. The education services provided at these schools require supplementary nursing care to allow the children and young people to fully access the educational curriculum and to achieve the best possible outcomes. The nursing care within Kent and Medway CCG is provided by Kent Community Healthcare Foundation Trust (KCHFT), Medway Community Healthcare (MCH) and Medway Foundation Trust (MFT).

There are 12 Special schools in Kent (and 1 in Medway) which cater for students with a range of special educational needs due to profound, severe and complex needs including learning difficulties, physical disabilities or behavioural problems. The total population of CYP in Kent & Medway aged 0-18 is 430,551 (Primary Care Information System as at 30th June 2019), of which approximately 3,429 (0.8%) attend a special school in Kent & Medway.

Local defined outcomes:

- CYP with complex needs are able to access school appropriately, consistently and safely;
- CYP and families feel engaged with the support provided by the service and contribute to planning in relation to the care that is provided;
- CYP feel empowered to manage their own health and well-being;
- Teaching staff are able to competently undertake appropriate health care interventions in school and have a good understanding of individual pupil's health and care needs to ensure that these needs can be met at all times.

The KCHFT CYP pharmacy team are working in a collaborative partnership with the nursing as an integrated health team across 10 schools in Kent and Medway. The purpose of the Special Schools Health team is to work in partnership with special schools to ensure CYP with complex health needs can access their education safely. The health team work collaboratively with the school staff empowering them through training, clinical and professional support to deliver the care of students which improves the school experience for the student.

This collaborative team working approach also reduces the amount of time that children cannot access school, increases school staff understanding of the level of need which keeps the child at the centre of care and provides a holistic approach to education and health.

It is the school governing body's responsibility to ensure that its school has policies/ protocols in place outlining clear processes for medicines management within the school. The Special Schools

pharmacy technician role is to support the safe implementation of medicines management within the schools.

The technicians work within the wider pharmacy service to support medicines management with the special schools in relation to:

- Policy development of a 'Medicines in schools' policy' across all named special schools in Kent
- Governance in relation to medicines management including developing documentation or implementation of appropriate software for the recording of administration of medicines in schools e.g. Medicines administration record (MAR) and auditing.
- Develop, review and deliver training to school staff which includes medication records on MAR charts in line with the current policy and governance arrangements.
- Support the special schools with the implementation of any national and local guidance e.g. Department of Education and Department of Health and Social Care joint guidelines for:
 - Supporting Pupils with underlying medical conditions
 - Guidance for using emergency adrenaline auto-injectors in schools
 - Guidance on the use of emergency salbutamol inhalers in schools.
- Access to KCHFT medicines information enquiries through email and telephone so that staff can contact the CYP pharmacy team and be advised as to any questions/queries they may have in relation to medicines.

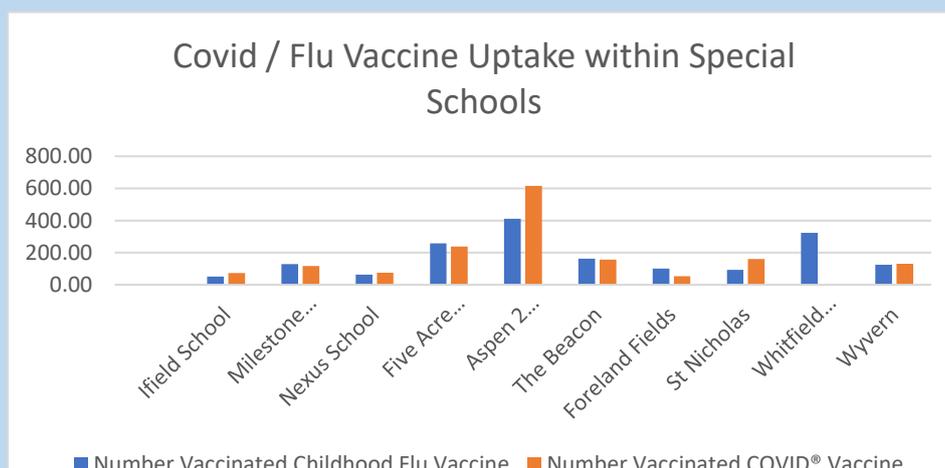
The KCHFT pharmacy team key medicines optimisation areas of focus within this collaborative approach for the project has included:

- Staff Education and Training in medicines management
- Medicines Policy, Standard Operating Procedures and Documentation Development
- Clinical Medicines Review/Interventions
- Quality Assurance monitoring reviews.

Challenges encountered during project delivery:

Challenges faced included unforeseen delays to the start of the project due to supporting the mobilisation of the COVID-19 Vaccination Programme. However, the team demonstrated excellent resilience during this time and developed a plan to ensure that once we returned to our business as usual there were steps in place to ensure the project timelines were on track. The team also seamlessly integrated the COVID Vaccination Programme into the Special Schools work and supported the team with arranging the vaccination clinics including the preparation of vaccines as well as supporting school staff to work with the vaccinators in a way that best suited the children, young people and school environment with minimal distress and disruption. Uptake for majority of the schools for the COVID and Flu vaccinations were close to the local Kent and Medway average uptake (56%) and higher in some schools as illustrated.

Vaccination uptake figures for the 10 special schools



RESULTS AND DISCUSSION:

Medicines management Quality Assurance monitoring involved a baseline pre-audit of the sites at the outset, then followed up with a post project commencement audit to assess their compliance with the recommended guidance. The pre and post audit results below provides a graphic representation showing level of improvement following appropriate specialist pharmacy service support in areas including medicines management training, expert pharmaceutical advice, medicines related clinical interventions, guidance and support in policy and standard operating procedures (SOP) development to improve standards across the schools. Four of the schools have demonstrated meeting above the 90% threshold for medicines management standards and two schools achieved 87% post implementation in comparison to pre-project review that identified a number of the schools were significantly below this threshold as outlined in Figure 1 below.

Following the baseline audits, the primary focus at the outset was to develop an overarching medicines policy through co-production with head teachers from all schools and the nursing teams. This was then followed by the development of bespoke SOPs for each school alongside the delivery of training in a blended format which included face-to-face, virtual and eLearning sessions as outlined in Table 1 below. Foreland Fields School was the pilot for eLearning with 100% of staff accessing this platform. Sessions highlighted in blue were delivered by either pharmacy or nursing teams during COVID-19 pandemic restrictions when the pharmacy team were also responsible for supporting the COVID-19 Vaccination Programme. A total of 1182 staff were trained across all 10 schools through the various training formats with the virtual sessions being most accessed (948 staff) due to the COVID-19 pandemic restrictions and approximately 60% of the training being delivered by the pharmacy team.

TABLE 1: TRAINING SESSIONS PROVIDED

Name of School	Attendance at Virtual Sessions	Attendance at Face-to-face sessions	eLearning access
Ifield School	10	7	Available June 2022
Milestone Academy	98	2	Available June 2022
Nexus School	NIL	53	Available June 2022
Five Acre Wood School	218	NIL	Available June 2022
Aspen 2	NIL	19	Available June 2022
The Beacon	221	1	Available June 2022
Foreland Fields	NIL	NIL	120 (pilot school)
St Nicholas	148	5	Available June 2022
Whitfield Aspen	82	NIL	Available June 2022
Wyvern	171	27	Available June 2022
TOTAL TRAINED: 1182 staff	948 virtual	114 face-to-face	120 eLearning

FIGURE 1: QUALITY ASSURANCE REVIEW FOR MEDICINES STANDARDS

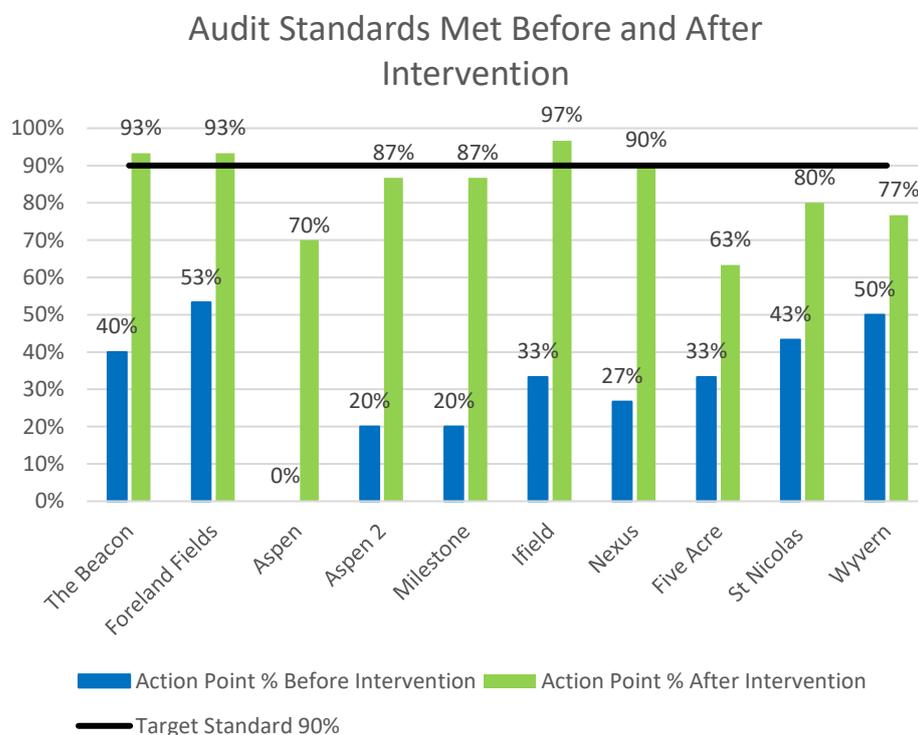
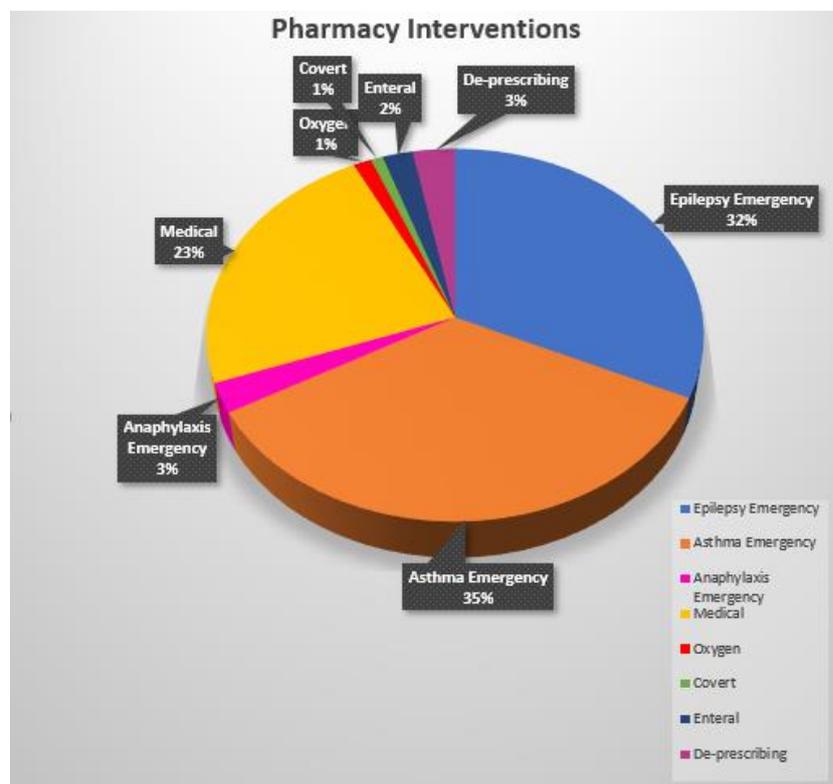
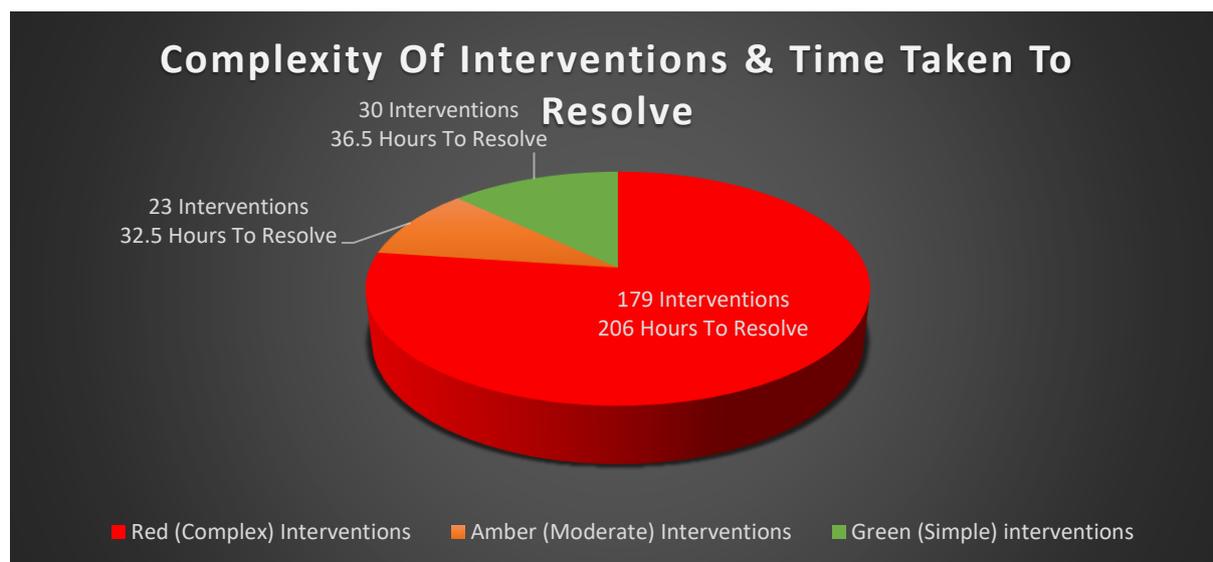


FIGURE 2: CLINICAL PHARMACY INTERVENTIONS



Clinical Interventions undertaken by the team across all the schools over a 6-month period has been broken down in Figure 2 above. A total of 232 interventions were made. Key areas where significant interventions were highlighted included emergency medication plan reviews for asthma (35%), epilepsy (32%) and specialist medical emergencies (23%). Figure 3 below highlights the level of clinical complexity and the total time taken by the team to complete these interventions.

FIGURE 3: COMPLEXITY OF INTERVENTIONS AND TOTAL TIME TO RESOLVE



Co-production complex intervention example:

In order to understand the complexities of the types of interventions encountered, an illustrated example is presented below which highlights the importance of co-production with key stakeholders including parents/carers, school, nursing, pharmacy and care agency to support the safe administration of medicines in school.

Child X is 4 years old and was due to start nursery at one of the special schools. Their current medical diagnosis and list of medicines were as follows:

Diagnosis:

1. Severe Epileptic Encephalopathy, Early Infantile Epileptic Encephalopathy (EIEE) type 13, related to mutation of SCN8A (variant mutation) presenting with refractory tonic-clonic seizures with apnoeas, continuous tremors and jittery movements and global developmental delay. Home oxygen for seizure related needs for oxygenotherapy.
2. Portacath (central line) for emergency use only.
3. History of recurrent infections including multiple central line infections caused by multiple resistant bacteria, pseudomonas colonisation. Candidal mucositis (candidiasis) affecting oral cavity and refractory to Nystatin.
4. History of Necrotising enterocolitis in neonatal period requiring surgery. Frequent episodes of diarrhoea on PEG feeding with no sign of suction and in absence of infection. Currently

tendency to constipation on mixture of blended diet and cows' milk-based liquid enteral nutrition preparation.

5. Gastro-oesophageal reflux disease.
6. Mild atopic eczema, flareups of fine rather macular pinkish rash in hot weather, excessive sweating.
7. Severe scoliosis, rapidly evolving due to dystonia.
8. First event of aspiration pneumonia at 3.5 years old.

Allergies: Tegaderm®, Steri-strips®

Medicines:

1. **Phenytoin 60mg/10ml Oral Suspension:** 8.0ml/48mg three times a day (Phenytoin monitoring level aimed at 24-34mg/L)
2. **Acetazolamide 250mg tablets:** 125mg three times a day (tablets to be crushed)
3. **Oxcarbazepine 60mg/ml Liquid:** 360mg (6ml) twice a day
4. **Clonazepam 2mg/5ml oral suspension sugar free:**
 - 0.5mg (1.25ml) at 03:00 and 11:00
 - 0.5mg (1.5ml) at 15:00 and 19:00
 - Another PRN (when required) dose of 0.5mg (1.5ml) to be either given in the gap between 19:00 and 03:00 or replace 0.5mg dose at 03:00 and 11:00 - for irritability, jitteriness, multiple mild seizures (not earlier than 3 hours after last dose of Clonazepam).
5. **Clonidine 50microgram/5ml liquid, sugar free:**
 - 30micrograms three times a day at 07:00, 11:00 and 15:00
 - 40micrograms three times a day at 19:00, 23:00 and 03:00
 - Additional PRN dose 20-60micrograms in case of significant distress and extreme irritability.
6. **Melatonin 5mg/5ml liquid:**
 - 6mg once a day in the evening
 - 6mg can be given within the night at least 4hours after previous dose.
7. **Choral Hydrate Oral solution: 400mg when required if Melatonin loses effectiveness, currently not given.**
8. **Omeprazole 20mg/5ml oral suspension:** 20mg (5ml) once a day in the morning.
9. **Sodium Chloride 0.9% solution via nebuliser:** 5mls every 4 hours

Symptom Management:

- **Glycerin suppository 2g** when required, maximum once a day to manage constipation. If needed regularly then replace with **Movicol® Paediatric sachets:** 1 sachet per day with further escalation to 2 sachets per day if required or reduction to half a sachet per day if 1 sachet is too much.
- **Paracetamol 120mg/5ml oral liquid:** 180mg (15mg/kg) via PEG 7.5mls up to 4 times a day for pain or fever
- **Ibuprofen 100mg/5ml liquid:** 100mg up to three times per day for pain or fever
- **Gaviscon® liquid:** 5mls up to four times per day via PEG for exacerbated reflux

- (Hyoscine patches were replaced by Glycopyrronium Bromide which was then discontinued during stay in PICU)
 - Cetirizine liquid: 5mg monthly in the evening twice a day based on the level of eczema flareup or any other itchy rash.
10. **Supplements:** Sodium Bicarbonate Liquid: 15mmol twice a day
11. **Prophylactic Antibiotics:**
- Azithromycin 200mg/5ml liquid: 100mg once a day on Mondays, Wednesdays and Fridays – to be continued over quarantine period for COVID-19 alternate weeks. Break during warm/hot season and then restarted no later than October.
12. **Rescue Medication:** Separate Epilepsy Emergency Medicine Management Plan

Background:

Epilepsy in children with SCN8A variant mutation causing EIEE13 is lifelong and resistant to medications. Seizures in children with SCN8A variant mutation causing EIEE13 are frequent and occur multiple times a day. Child X therefore has a double-handed care package with 24/7 care provision where the carers accompany child X to school.

Child X has several medications whilst at school, and these are needed within the school day. Previously the medications have been coming into school already drawn up by and administered in school by the agency staff. In doing so it was the agency's responsibility, and all parties (agency, school, and parents) had a contract in place outlining the arrangements. The school recognised this practice, kept a record, and were aware of the child's medicines and risk assessments had been carried out, but ultimately the agency looked after the medications when caring for child X at school.

However, it recently came to light that the medicines are being drawn up by the parents at home at the start of the day (very early morning) and then the agency staff were administering the pre-drawn medication during the course of the school day (up to 8 hours later). In light of this practice, it had raised several new risks in relation to the efficacy of the medicines as well as overall medication safety at school.

Actions taken:

The pharmacy team worked closely with all parties to fully understand how this practice had been established. This involved several individual meetings with parents, carers and school. Following this a detailed medicines information enquiry around the stability and safe administration practice for each drug was completed.

The findings were as follows:

“Following the research and clinical review, please see summary information below regarding administration and storage of medications prior to use via a PEG tube.

The primary research was conducted using the manufacturer's Summaries of Product Characteristics (SmPC), Martindale: The Complete Drug Reference, Handbook of Drug administration via enteral feeding tubes, NEWT Guidelines as well as company Medical Information departments.

Clonidine - The manufacturer does not hold any stability data for products stored at unknown temperatures and drawn up in a syringe for 4-8 hrs before administration. They recommend discarding the product in the syringe. Using the medication other than how it is licenced makes it off licence.

Sodium bicarbonate 84mg/ml (1mmol/ml) - The manufacturer does not hold any stability data for products stored at unknown temperatures and drawn up in a syringe for 4-8 hrs before administration. They recommend discarding the product in the syringe. Using the medication other than how it is licenced for use makes it off licence.

Clonazepam 2mg/5ml (Rosemont) – company would not advise drawing up and leaving in syringe as no stability data to support it. Only stability data is for in the amber glass bottle.

Acetazolamide (tabs, Andipharm/Advanz/Mercury Pharma) - the SmPC of Acetazolamide 250mg Tablets makes no reference to manipulation or mixing of the finished product into an alternative compound to facilitate administration via a nutrition tube; this would be off-license use. ADVANZ PHARMA have not conducted any studies to assess the stability, efficacy or safety of Acetazolamide 250mg Tablets when crushed and dispersed. ADVANZ PHARMA does not recommend the use of the product outside the product licence. Using the product in this way needs to be checked with the doctor.

Phenytoin 30mg/5ml suspension (Upjohn, was Pfizer) - Phenytoin administration via enteral feeding tubes is notoriously problematic. Studies have shown that recovery and gastrointestinal absorption of administered doses is unpredictable, interaction with enteral feeds can affect bioavailability, and therapeutic levels achieved with treatment are frequently much lower than expected. Information to be shared with the prescriber. No testing has been done on product storage outside the bottle, therefore the company cannot recommend.

Phenobarbital - no data on use in syringes or any storage outside of the bottle.

Movicol® – each sachet should be dissolved in 62.5ml of water. Reconstituted solution can be kept for 24 hours in the fridge. Macrogols have been given via enteral feeding tubes without apparent ill effect. The patient should be monitored for appropriate effects, both of the laxative, and of any other medication which the patient may be receiving enterally.

Ibuprofen - no data on enteral use of generic products. If the patient is being prescribed Brufen® then the syrup should be mixed with an equal volume of water prior to administration via a feeding tube to reduce the viscosity and reduce resistance to flushing down the feeding tube.

Paracetamol – the viscosity of the paediatric liquid preparations is very high; it is difficult to administer these suspensions via a fine bore tube without dilution.”

Following our findings, a wider multi-disciplinary meeting was held with parents, care agency, school staff, nursing and pharmacy involvement to understand the current situation fully, review the findings and agree a mutually acceptable way forward that promoted medication safety in school. It was imperative for our team to ensure that child X’s parents were an integral part of the co-production so that they were part of the decision-making process.

A positive outcome was reached which included:

- School to order lockable medicines trolley for use in school

- Pharmacy to support with medicines reconciliation and clinical interventions with consultant for school requirements
- Consultant has agreed to provide 2 sets of prescriptions so that school and home have independent supplies – pharmacy to support family to arrange.
- School to pilot trolley use in the new term and feedback at follow-up meeting.

CONCLUSION:

The importance of Medicines Optimisation in Special Schools

Medicines optimisation is about helping people to get the best outcomes from their medicines. It describes systems and processes used by staff, working in health and social care, which ensure that people receive the best possible care with medicines¹⁶. Smith et al¹⁷ identified medication related issues such as the adverse effects of medication being highlighted as a cause of both non-adherence and poorer school performance by CYP and parents/carers. This growing evidence base⁸⁻¹⁸ further reinforces the need and importance of medicines optimisation in special schools through structured commissioning and collaboration with community pharmacies to provide:

- Repeat prescription service
- Effective medication reviews which includes considerations for deprescribing
- MAR Chart provision
- Medicines Information and Counselling
- Provision of suitable emergency medicine kits for salbutamol and adrenaline auto-injectors in schools.

These small but significant steps will support schools not only to effectively manage medicines that are essential during school hours but also support CYP to get the best outcomes from their medicines thereby promoting medicines safety in schools.

How can community pharmacists support?

Reducing health inequalities and improving health and wellbeing are major priorities for pharmacy. Pharmacists' skills of listening, explaining, advising and questioning are all highly relevant to help identify and support the medicines optimisation needs of CYP with complex health needs in special schools. Community Pharmacists are local, accessible and ideally placed to develop close links with CYP, families and their schools:

- ✚ To support safe and effective management of medicines to CYP in school to minimise the risk of errors through medication reviews and the provision of MAR charts if appropriate.
- ✚ To effectively manage the supply of medicines for long term medical conditions in CYP improving monthly repeat prescription management and minimising waste.
- ✚ To help provide access to medicines information and answer questions related to individual children's medicine needs from parents/carers.

- **Medication Use Reviews (MUR) / New Medicine Service (NMS) and MAR chart provision**

In CYP, medication adherence may be influenced by a number of factors: parents/carers beliefs about the condition, the treatment regimen, child resistance, relationships within families, desire to preserve normal life and input from healthcare professionals¹⁸. Improving medication regimens has been shown to improve disease outcomes in CYP¹⁹. Aston et al¹⁸ identified that MUR (23.7%) and NMS (28.9%) services are utilised by community pharmacists in CYP/their carers. Respondents in this study also highlighted school related adherence issues relating to the need to take a medication at school and information requests to inform both parents and school included:

- ❖ the timing of doses
- ❖ dose instructions about whether to take it with or after food
- ❖ could the taste be improved
- ❖ potential side effects.

The KCHFT pilot¹⁴ highlighted the importance of standardised MAR chart provision to support the safe and effective administration of medicines in school. Community pharmacists are ideally placed having access to robust dispensing software tools to

- ❖ provide a repeat prescription dispensing service, minimising waste
- ❖ dispense separately labelled supplies for home and school where appropriate
- ❖ provide up-to-date MAR charts to parents/carers/schools.

- **Providing medicines information and access to resources including leaflets, dispensing labels and medicines related advice for parents and schools including advice and support on:**

- ❖ Medicines administration, dosing intervals
- ❖ Medicines administered via specialist medical devices
- ❖ Emergency medicines at school for asthma and anaphylaxis
- ❖ Advising on off-label and unlicensed use of medicines when appropriate including provision of supporting information such as leaflets from accredited paediatric specialists e.g. www.medicinesforchildren.org.uk²⁰

The existing barriers in the current system include:

- limited financial resources within schools¹⁵
- increase in medication related errors due to the increased burden and responsibility on teaching and support staff to undertake medicines administration tasks^{15,16}
- a perceived lack of funding in the current commissioning structure for a specialist pharmacy led service to special schools^{7,15}

A specialist pharmacy service for special schools relies on the need for a review of the existing commissioning processes and funding nationally to standardise and fully meet the medicines optimisation needs in these schools across England. However; community pharmacists^{Appendix 4} can still play a pivotal role in supporting not only CYP and families but also teachers and healthcare professionals working in this setting to promote a more localised approach to quality improvement initiatives around medication safety at home and in schools. The Department for Education alongside the Department for Health and Social Care need to ensure that there is a structured

commissioning pathway within the SEND and mainstream health provision to enable all CYP and families to have equitable access to specialist services including medicines optimisation.

The next steps for the KCHFT CYP Pharmacy team...

Our next steps include continuing to build on this work locally and also support other special schools/pharmacy teams nationally through collaboration and sharing innovative practice as well as lessons learned. Closer integrated working with pupils, parents and carer involvement in focus groups are planned for the next academic year.

To support this work on a national and strategic level, the project lead has presented to MPs in the Westminster Forum in September 2021 when the SEND Policy review was being discussed. Following this, invitations to speak at several schools and forums across the UK are planned throughout 2022 with the first one taking place in Greater Manchester.

A FutureNHS Workspace^{19,20} was recently set up for [medicines optimisation in special schools](#) to enable the collaboration to reach a wider audience through active engagement/ networking which will include working with national organisations such as National Association for Special Education Needs (NASEN).

Closer integrated working with pupils, parents/carers involvement and co-production through focus groups are also planned for the next academic year. Medicines education sessions run by the pharmacy team will be integrated into the school parents' evenings to highlight critical information relevant to their schools, alongside the publishing of regular newsletters for each term on medicines related topics relevant to the local population for individual schools.

Recently, we have also been approached by mainstream schools that have CYP with learning disabilities and complex health needs during school hours. As the need continues to grow, our intention is to ensure that local commissioning structures are made aware in order to review support for these mainstream schools too.

Tackling health inequalities is one of the key outcomes for the new NHS landscape that we are all embarking into with the development and implementation of Integrated Care Systems (ICS). To support this agenda further, the team also plans to undertake more structured medication reviews with a primary focus on the STOMP-STAMP programmes²¹.

STOMP-STAMP²¹ was launched in December 2018 by NHS England and The Royal College of Paediatrics and Child Health. The following organisations listed below made a pledge at the launch event:

- The Royal College of Paediatrics and Child Health (RCPCH)
- The British Association of Childhood Disability (BACD)
- Council for disabled children (CDC)

The pledge was:

We pledge to ensure that children and young people with a learning disability, autism or both are able to access appropriate medication (in line with NICE guidance,) but are not prescribed inappropriate psychotropic medication. Regular and timely reviews should be undertaken so that the effectiveness of the medication is evident and balanced against potential side effects. This will mean that children and young people are only getting the right medication, at the right time, for the right reason.

We, the undersigned, pledge to work together with children and young people with a learning disability, autism or both and their parents, carers and families, to take measurable steps to ensure that children and young people only receive medication that effectively improves their lives.

We pledge to set out the actions that our individual organisations will take towards this shared aim and report regularly on the progress we have made, ensuring that we can be held to account.

What is STOMP and STAMP?

CYP with a learning disability, autism or both are more likely to be given medication (including psychotropic medication) than other CYP.

STOMP aims to stop the overuse of psychotropic medications for CYP with a learning disability, autism or both. It is about helping CYP to stay well and have a good quality life. If CYP do need psychotropic medication, it should be seen as the last resort. Medication should be regularly reviewed to make sure it is still the right thing for them and they do not stay on the medication for longer than is necessary.

STAMP aims to make sure that children and families can access other treatment and support when children display behaviours that challenge, for example Positive Behaviours Support or other therapeutic support. Sometimes when children and young people do need medication it can be difficult to make sure they are always able to get it when they need it. STAMP is about making sure where medication will help children and young people to have a good life, barriers are removed.

What are psychotropic medications?

Psychotropic medications are used to treat mental health conditions, such as anxiety, depression, and psychosis. Sometimes these medications are given to children and young people because of behaviours that challenge others. These medications can be right for some children and young people in some situations and can help them live a good life.

However, there are other ways of helping children and young people so that sometimes they need less medication or none at all. STOMP and STAMP want to make sure that children, young people and families get the other support they need. This might mean they are less likely to need psychotropic medication or need it for a shorter time. Psychotropic medication should not be used instead of support and therapeutic treatment.

What can organisations and individuals do?

STOMP and STAMP are about everyone working together to make sure children and young people get the right medication, if and when they need it. Organisations and individuals that work with children and young people with a learning disability, autism or both are showing their commitment to STOMP and STAMP by signing a pledge. This will help them to make sure children and young people get the: **Right medication at the right time for the right reason.**

Overprescribing is not a new problem and a lot of great work has been done to address the issue. Healthcare professionals and NHS managers have been developing strategies for many years, and together with scientists, policymakers and patient representative groups have contributed to building up our understanding not only of the problem, and its consequences, but also of ways to tackle it.

The key to stopping overprescribing is medicines optimisation: ensuring that patients are prescribed the right medicines, at the right time, in the right doses.

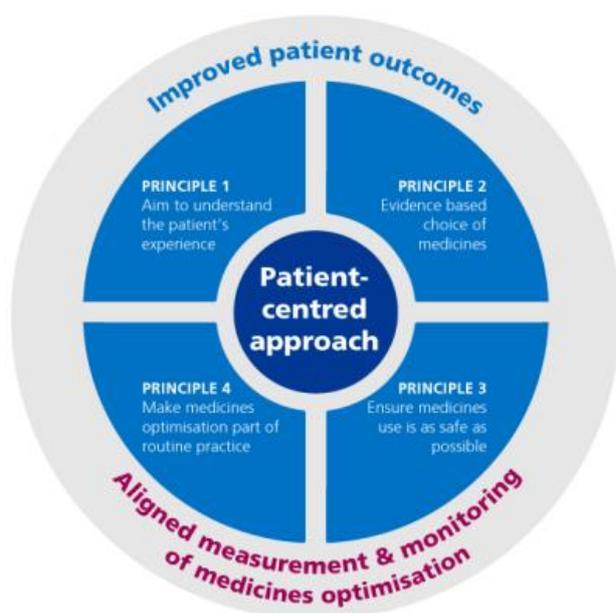
In some cases, medicines optimisation may lead to a patient being offered additional medication, or having their dose increased, but it also provides a framework for reducing and stopping overprescribing.

Medicines optimisation is based on four principles:

- aim to understand the patient’s experience
- evidence-based choice of medicine
- ensure medicine use is as safe as possible
- make medicines optimisation part of routine practice.

Alongside these four principles, there is the overall aim of better patient outcomes, and the foundation that medicines optimisation must be centred on the needs and preferences of the patient and depends on effective measurement and monitoring. Supported by the NICE Quality Standard for Medicines Optimisation, this can be best captured in the diagram in Figure 4 below.

Figure 4: The key principles of medicines optimisation.



Through the above principles, the pharmacy team intend to implement phase 2 of the quality improvement project with a CYP and families centred approach through increased collaboration and co-production with key stakeholders to continue to ensure the safety of medicines in school as well as raise awareness, sharing learning on a strategic and national scale.

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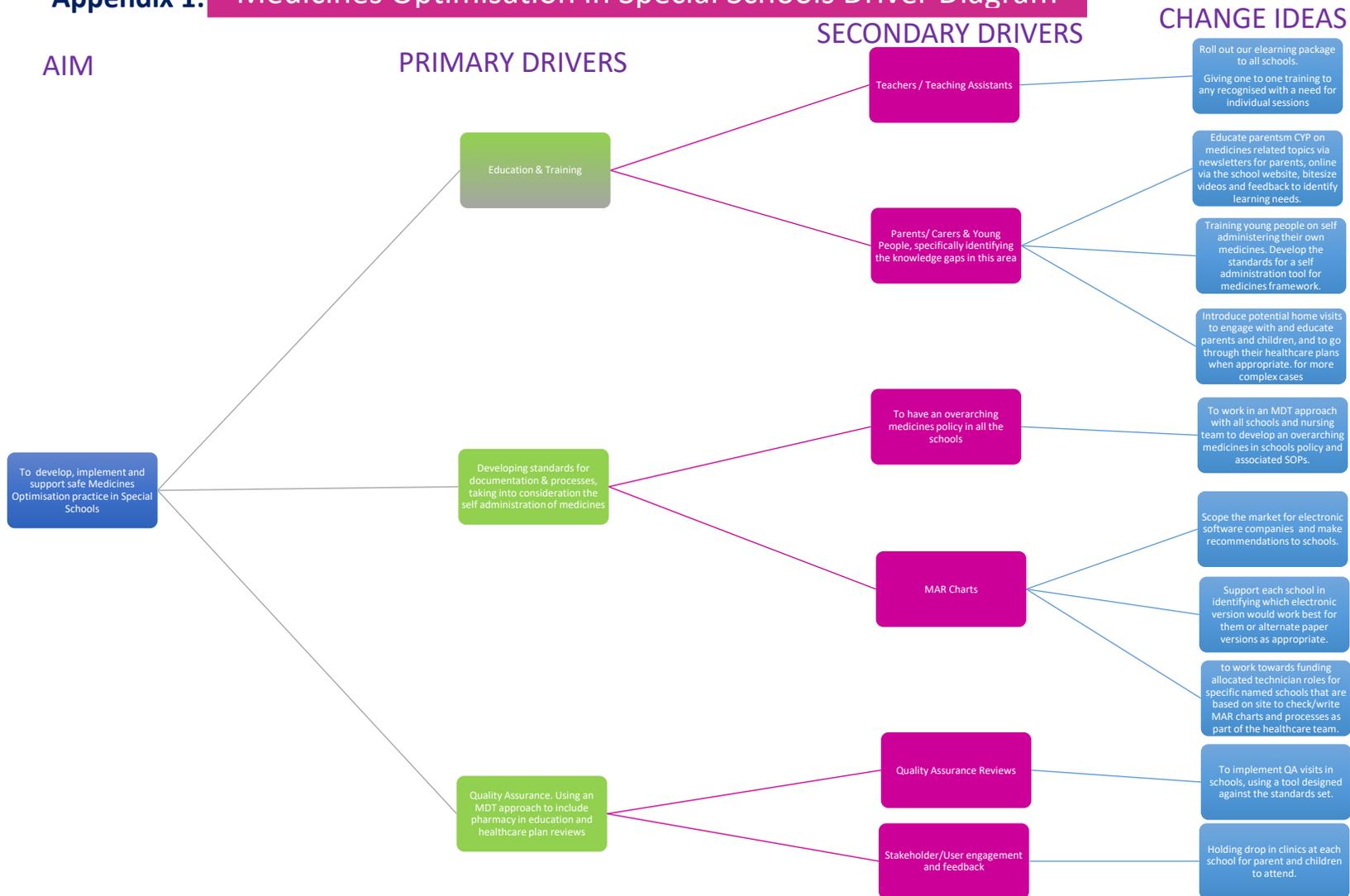
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APPENDICES:

Appendix 1: Medicines Optimisation in Special Schools Driver Diagram



Appendix 2: PDSA Cycle for Quality Assurance Monitoring

Following feedback received the plan for the next round of audit includes a documentation review for MAR charts against the RPS standards and considerations for ongoing self-assessment by school staff.

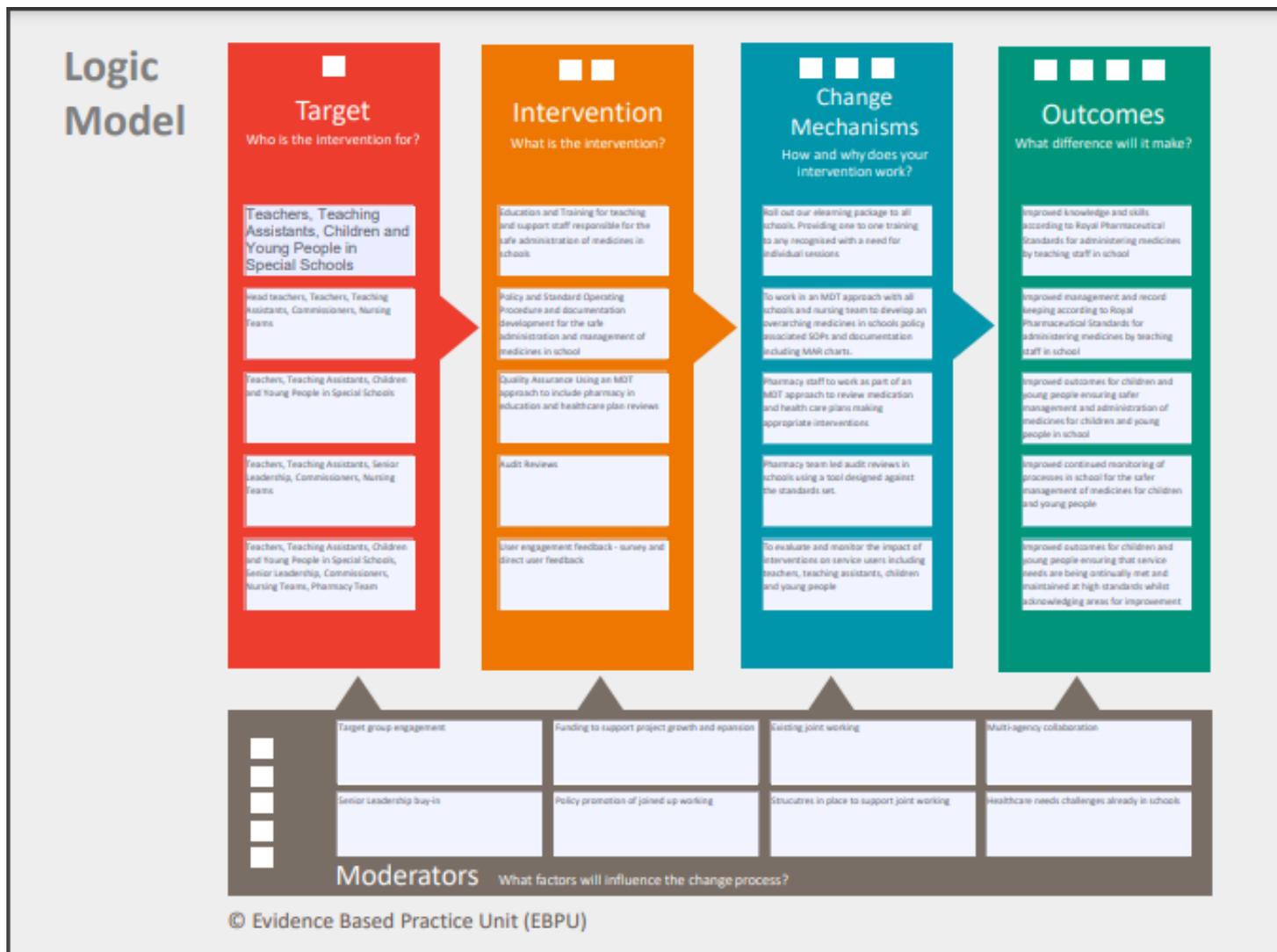
Reviewed and developed a bespoke quality assurance monitoring review that is able to assess whether schools are meeting the minimum best practice guidance and in compliance with the law for the safe administration of medicines.



Discussed and shared findings with both the school and nursing teams.

Pharmacy technician completed site visits for all 10 special schools which were reviewed by the pharmacist.

Appendix 3: Logic Model



Appendix 4: References, Recommendations and Best Practice Tips

KEY REFERENCES, RECOMMENDATIONS AND BEST PRACTICE TIPS FOR COMMUNITY PHARMACISTS

Key References from the Department for Education:

- **‘Supporting Pupils at School with Medical Conditions’** which is statutory guidance for governing bodies of maintained schools and proprietors of academies in England. Available here: <https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>
- **“Emergency asthma inhalers for use in schools”** Since 1 October 2014 UK schools have been allowed to purchase a salbutamol inhaler without a prescription for use in emergencies when a child with asthma cannot access their own inhaler. *There is useful recommended information for community pharmacists on what needs to be included in the emergency kit.* Available here: <https://www.gov.uk/government/publications/emergency-asthma-inhalers-for-use-in-schools>
- **“Using emergency adrenaline auto-injectors in schools”** From 1 October 2017, schools in England have been allowed to purchase adrenaline auto-injector (AAI) devices without a prescription, for emergency use on children who are at risk of anaphylaxis but whose own device is not available or not working. *There is useful recommended information for community pharmacists on what needs to be included in the emergency kit.* Available here: <https://www.gov.uk/government/publications/using-emergency-adrenaline-auto-injectors-in-schools>
Another useful resource to help when supporting schools with emergency AAIs is the “spare pens in school” website providing useful information for parents, schools and pharmacists. Available here: <https://www.sparepensinschools.uk/for-pharmacists/>

Recommendations and Best Practice Tips:

- **Actively identify and promote medication reviews / new medicine service for CYP in your pharmacy.** Communicate all interventions made with parent/carers, key healthcare professionals (GP, consultant, specialist nurse) and lead in charge for health at the school to ensure this is noted on the relevant education and health care plan for the child.
- **Actively promote self-administration of medicine through supporting CYP who are competent and confident with medicine administration to independently manage their medicines at home and in school to improve compliance and adherence** e.g. good inhaler technique for asthmatics or self-administration of insulin.
- **Engage with your local authority and NHS community health service Trust pharmacy team to build collaborative working relationships** when making interventions and providing MAR charts.
- Where possible and appropriate to do so **liaise with GPs to obtain separate prescriptions for supply of medication for home and school.** This will enable school to receive a unique supply that is correctly labelled for the duration of the school term e.g. *some special schools offer boarding/residential facilities – in such settings a separate supply for school may be deemed appropriate especially if home and school are not local to each other.*
- Many medicines prescribed for use in children with complex health needs are **“off-label” or “unlicensed”** e.g. when administering medicines via enteral feeding tubes. Parents, patients and teachers, and others in loco parentis, require information about medicines. The information must be given in a way they can understand, and be accurate and consistent. Given the complexity of therapeutic and pharmacological information, and the burdens upon those giving and receiving it, the need is for sound, practical and sensible arrangements for communication, supplemented by readily available sources of reference. The Medicines complete website provides a comprehensive digital suite of information including the BNF/BNFC and Drug Administration via Enteral Feeding Tubes. Available here: <https://about.medicinescomplete.com/> However, another useful paediatric accredited website is “Medicines for Children”. Available here: www.medicinesforchildren.org.uk
- Join [FutureNHS Medicines Optimisation in Special Schools Workspace](#) to share learning & best practice.

Appendix 5: Service Experience

Recommendation letter from Foreland Fields School:

"Dear Nirusha,

It is my pleasure to write to you to give formal detail on the benefits that your service has provided for Foreland Fields School.

Policy and practice: *Nirusha and her team have provided a full and thorough analysis of our policies working closely with us to ensure they meet national and county guidance, but also that they fit the needs of our school. Included in this was an audit of our current practice, which was excellent as it provided us with external validation of our practice. The report that followed this up was detailed and effective in providing next steps for development. I have been amazed at the time and commitment that has been put into the support that we have received. I cannot think of any other training organisation that has provided our school with this level of support. Not only are the team experts in their field, but they understand the need to work closely with school to understand their setting.*

Training: *Staff feedback from the training sessions is overwhelmingly positive. The expertise from the team is so obvious that it makes staff want to listen and also encourages the acceptance of change of practice when this is required. Training is truly bespoke, from the creation of resources to the delivery of the training.*

Advice line: *This is very helpful as it provides quick, yet detailed answers from experts. I highly recommend this service.*

We will continue to work with Nirusha and her team and consider this service to be highly effective.

Thanks again.

Jeremy Edwards, Deputy Head teacher"

Email Milestone Academy for overall service experience:

"Hi Vanessa,

Having access to the NHS Special School Pharmacy Service is the bonus service we did not know we needed; it has really added value and improved our practice. Since working with this service, we have improved our protocols around medication administration, our knowledge of medications, we have reduced the amount and type of medications given in school. The service is practical and helpful especially around medication queries & epilepsy / asthma plans. The technicians and pharmacists are always available and can be relied upon to get back to us to deal with enquiries and problems promptly. The staff are able to liaise with families, GPs and specialists regarding medication or specialist plans such as epilepsy and asthma. This has made a big difference and helps keep everyone safe and healthy. Through this collaboration, we have identified our next steps which include:

- to consider our next phase of medication management in some classes*
- staff & family engagement. As a service they are keen to work with and support the whole family with medication issues so this really fits*
- More medication training particularly around off-site visits and school journeys*

I have every confidence the above and more will be achieved with the specialist pharmacy service in place."

Liz Skilton, Speech & Language Therapist

Director of Integrated Pupil Services (Therapy & Health Team Lead)