

CYANS Interim Report to NDP Monitoring Group February 2013

Executive summary

CYANS was established in June 2011 to lead improvements in paediatric allergy care following a review of allergy services in Scotland by the Scottish Medical and Scientific Advisory Committee (SMASAC) in 2009.

In a departure from the standard national managed clinical network (NMCN) model two discreet phases were outlined; the first was an initial two year programme of work, supported by a Paediatric Allergy Advisor, focused on establishing the evidence base for a sustainable and coordinated pan-Scotland approach to the ongoing development and delivery of allergy care with appropriate involvement of community, DGH and specialist services.

With recurrent funding for a Lead Clinician and Administrator CYANS is structured and governed in line with extant SGHSC guidance on Managed Clinical Networks to optimise efficiency and effectiveness.

Based on its findings, CYANS is scheduled to report recommendations, including the future status of CYANS, to the Scottish Government in June 2013.

Phase 2 will focus on implementation of these recommendations.

Phase 1 (June 2011-13):

With an agreed emphasis on anaphylaxis and severe food allergy, CYANS has successfully achieved its immediate priorities:

- CYANS launch and family events.
- Effective engagement with key stakeholders to inform future service provision with a total of over 500 contacts across Scotland.
- Effective stakeholder communication systems including a CYANS Website and Newsletters.
- Agreeing recommendations for anaphylaxis and food allergy care for children and young people.
- Mapping exercise of current allergy service provision across Scotland.
- Analysing the allergy education and training needs of clinicians in both primary and secondary care and developing appropriate training solutions.
- Developing an Allergy instance of the Clinical Audit System (CAS) to audit allergy service provision and enable quality improvement.

In March 2013 work will begin to trial an allergy education & training programme for health professionals from primary care across Scotland and to begin data collection.

Satisfactory progress has been made on establishing the evidence base for improvements in allergy care in Scotland and to finalise recommendations to the Scottish Government.

Phase 2 (June 2013 onwards):

As a result of the work undertaken by CYANS to date the scale and priorities of the work to be done to deliver Scottish Government aims in relation to specialist allergy care in Scotland are now much better understood and the focus of CYANS work will be on implementation of recommendations on:

- Standards of allergy care.
- Patient pathways.
- Models of allergy service provision.
- Allergy education and training for health care professionals.

It will include:

- Establishment of educational mentorship and service support arrangements.
- Provision of initial audit and evaluation of data collected on the CYANS Allergy Database, extend data collection to severe food allergy and establish clinically relevant audit tools.
- Implementation of allergy education & training solutions for clinicians.
- Gaining feedback from children, young people and their families on the early impact of CYANS' recommendations and work.

It is recognised that these developments in specialist allergy care are in a crucial phase and successful delivery of these objectives requires a continuing pan-Scotland approach, continued support by the allergy advisor post which provides essential clinical experience of allergy and allergy services and that CYANS is well placed to lead and coordinate this work.

CYANS report to Scottish Government will therefore include a recommendation that CYANS be designated as a National Managed Clinical Network with continued funding of the allergy advisor post for one further year, followed by funding for a network manager. Details of the resource implication are outlined in section 4.3

1 Introduction and background to CYANS

1.1 Epidemiology

Allergy affects an estimated 25-30% (up to 1 in 3) of children and young people in Scotland, with 6% of children estimated to develop food allergy.

It is important to note that paediatric allergy is different from a number of other paediatric specialist services in that there are large numbers of children and young people with allergies. Although the majority of children with allergies will have symptoms that are mild to moderate and can be managed adequately within primary care, there is a considerable group of children and young people, approximately, 2-3% with severe allergic diseases, including multi system allergic disorders affecting several organs in the same person. These children require treatment by clinicians specialising in allergy, but at present access to specialised paediatric allergy services across Scotland varies greatly.

1.2 Policy / Evidence

Paediatric Allergy was identified as a specialty requiring support by the National Delivery Programme for Children's Specialist Services (NDP), as a result of several allergy reports including the House of Lords report (2007) and the Scottish Medical and Scientific Advisory Committee (SMASAC) report (2009), all supporting the development of a National MCN approach to improve allergy service provision across Scotland. A recent report from the North West England Allergy and Clinical Immunology Network (2011), has been very encouraging and has evidenced the benefit of this approach, but acknowledges that "it is important to note that these networks are not a quick fix but a more long term solution to the problems surrounding allergy service provision".

In 2010 NDP funding was secured to develop a paediatric allergy Network. As a result CYANS was established in June 2011 to lead and support services in improving standards of clinical care of children through the establishment of continuous quality improvement systems and processes.

1.3 Purpose of CYANS

The purpose of CYANS was to establish the evidence base and make recommendations for future provision of specialist allergy care, including the role of the national network.

Two discreet phases were envisaged:

Phase 1 – Project phase to establish the evidence base and report to Scottish Government its recommendations. Thereafter, Phase 2 would focus on implementation of the recommendations. CYANS is a unique NMCN in that there are potentially large volumes of children and young people affected by allergy with very few specialist clinicians trained in allergy across Scotland.

To ensure that this work was achievable within the 2 year project phase; CYANS prioritised the work to focus on anaphylaxis and immediate type allergy to foods. In the longer term CYANS intends to include work on complex multi-system allergy and immediate type allergy to latex, insect venom, and drugs.

2 CYANS Objectives

In the initial 2 year project phase CYANS aims were to:

- Develop a model of high quality allergy care; develop recommendations and define patient pathways of care for primary, secondary and tertiary care

including development of transition pathways for young people to adult services.

- Define the education and training needs for health care professionals delivering paediatric allergy services and identify training solutions.
- Develop an allergy database to aid service planning, audit and research into allergy.
- Review service provision for highly specialised allergy services.
- Improve communication and information sharing with all CYANS stakeholders.

Delivery of the CYANS work plan is through five work streams, overseen by a steering group, with outputs summarised below:

2.1 Models of Allergy care

- Recommendations for anaphylaxis management and management of food allergy have been developed based on relevant local, national and international guidelines and approved by the CYANS steering committee.
- Recommendations for allergy service provision are being developed based on the results of the mapping exercise of allergy service provision across primary and secondary care for children and young people throughout Scotland.
- Transition pathways of care for young people are being developed.

2.2 Education & Training

- Recommendations for allergy training have been developed based on the results of the scoping exercise to identify the education and training needs of health care professionals relating to allergy.
- A review of existing allergy educational and training packages and materials that are currently available has been undertaken.
- A pilot allergy training programme is scheduled for February/March 2013 involving clinicians from primary care.

2.3 Continuous Quality Improvement

- Remit agreed with an initial focus on data collection specific to anaphylaxis, with plans to extend data collection to food allergy during 2013.
- Clinical Audit System has been adapted ready for use, training materials have been developed and an initial cohort of staff has been trained.
- A core data set page to collect data specifically on anaphylaxis has been approved and is currently under development by NISG, it is anticipated this page will go live in February 2013.
- A programme of database training has commenced and is being rolled out across all health boards.
- Piloting of the database will commence in March 2013 and initial audit of baseline data will be collected retrospectively.

2.4 Communication and Engagement

- A communication and engagement strategy has been developed and links with key stakeholders have been established.
- A CYANS website has been developed and is routinely updated.
- Focus groups of parents, children and young people are regularly consulted to provide design and content ideas for the 'families' and 'young peoples' sections on the website.
- CYANS regularly publish newsletters to keep stakeholders informed of its progress.

2.5 Parents and patient Involvement

- Views and experiences of patients and carers have been sought and shared at the launch and other engagement events, which have influenced CYANS priorities and work plan.
- Collaboration with Young Scot was designed to obtain views of young people on allergy service provision and needs for transition services.
- A service users report is currently being written and will underpin CYANS' recommendations to the Scottish Government and will provide important feedback to the children, young people and their families who had input into the work of CYANS.

2.6 CYANS Achievements June 2011 - November 2012

(See appendix 1 for table of achievements for CYANS June 2011 – Nov 2012)

(See appendix 2 for projected work plan Dec 2012 – June 2013)

3 Implementation Phase

During the project phase it has become apparent that a distinct phase of implementation work will be required following the current project phase. Implementation of CYANS' recommendations will require further work and development during June 2013 - June 2014 as outlined below (**subject to continued funding**).

3.1 CYANS work plan July 2013 – June 2014

CYANS will;

- Develop and deliver road shows to Health Boards across Scotland in order to assist with the implementation of CYANS recommendations for improved allergy service provision, this will be ongoing throughout 2013/ 2014
- Evaluate the efficacy of the allergy education pilot for primary care, and develop a sustainable allergy education and training programme for primary care based on these results during June - Sept 2013
- Support and look at ways to deliver allergy education for primary care clinicians across all health boards in Scotland - Oct 2013 - June 2014
- Develop, monitor and evaluate mentor support for clinicians to enable effective allergy education for clinicians - Ongoing throughout 2013 /14
- Develop, monitor and evaluate a clinical allergy support network to support clinicians in both primary and secondary care to provide high quality allergy care locally - ongoing throughout 2013 /14
- Organise and deliver service users workshops across Scotland to enable service users to feedback on the impact of CYANS work on allergy service provision - spring 2014
- Audit and evaluate the data collected on CYANS -Allergy database, to provide valid baseline data of allergy service provision in Scotland and develop

clinically relevant audit tools for quality improvement - ongoing throughout 2013/ 14

- Develop CYANS - Allergy database to collect information on severe food allergy and allow data collection on food allergy, providing base line data for Scotland Data collection from November 2013, Initial audit estimated May/June 2014
- Develop a practical resource package for food allergy in order to equip all primary care clinicians and general paediatricians with resources to treat and manage straightforward food allergy - throughout 2013/14.

(Also see appendix 3 for projected work plan July 2013 – June 2014)

4 The Future of CYANS

4.1 Recommendation for CYANS to become a fully-fledged national MCN

The successful work of CYANS' pan-Scotland project phase over the past 18 months has made it clear to the clinicians involved in the network and its steering group that, in order to reap benefit for children and young people with allergies across Scotland, CYANS will need to continue working as a National MCN in the longer term and will require short term support from the allergy advisor post in order to support and sustain the work of the NMCN in the longer term.

The situation in allergy is unusual, since despite the large numbers of children and young people affected by allergies, there are only a small number of allergy specialists and clinicians who focus on treating patients with severe allergies in Scotland.

It will only be through a national MCN that equitable access to allergy education and training, to educational allergy mentorship and to an "allergy service support network" can be provided to a wide range of health care professionals across Scotland enabling them to obtain the competencies required and to provide high quality allergy care in primary and secondary care.

In addition, quality improvement in allergy has to be supported by a national MCN to ensure that allergy care data is collected in a standardised format throughout Scotland, audited to identify any shortcomings and that recommendations for improvement are implemented, enabling best practice in allergy across Scotland.

Furthermore, the very successful programme of engagement of young people and parents of children with allergies from across Scotland which enables them to contribute their views and aspirations for the improvement and development of allergy services, and the provision of allergy information to service users through the CYANS web site will require ongoing support from a national MCN.

4.2. Proposal for continued funding for CYANS Allergy Adviser for the implementation phase

The CYANS NMCN will deliver recommendations to the Scottish government in June 2013. Early implementation of the CYANS recommendations and initial evaluation of

the impact of these recommendations on service provision are both critical for the success of CYANS, which aims to improve the quality of and access to allergy services for children and young people across Scotland.

In order to allow the effective implementation of CYANS' recommendations and initial evaluation, the CYANS steering group recommends continued funding for the allergy advisor post for a further year (from July 2013 - June 2014). This will enable CYANS to progress at the current rate whilst beginning the implementation of recommendations.

The allergy advisor role will provide credible clinical expertise in allergy and knowledge of allergy services enabling work to progress across the following areas,

Service provision

- Structure and set up a clinical "allergy service support network", which will provide a clinical evidence base, advice, guidance and relevant expertise to enable clinicians across primary and secondary care with less allergy expertise to provide high quality allergy care themselves, if appropriate, rather than having to refer on.
- Perform a review of existing transition pathways, inform the development of a transition pathway for young people to adult services for allergy and facilitate implementation of pathway within a pilot health board.
- Present CYANS' recommendations to health boards across Scotland ("roadshows") and maximise the uptake of the recommendations designed to improve allergy care for children and young people.

Education & training

Develop a workforce development programme that will:

- Assess the efficacy of the pilot education and training programmes currently being developed for clinical practice and based on evaluation and review of the pilot and evidence based practice, develop and improve allergy education packages.
- Based on results of the pilot education programme, facilitate the initial delivery of allergy focused training sessions using clinical expertise and evidence based practice in line with current guidelines, look at ways to support roll out across health boards and funding opportunities
- Identify clinicians with competence to support colleagues across primary, secondary and tertiary care, to offer an allergy education mentoring facility in Scotland which will support training opportunities (e.g. shadowing allergy clinics, skin prick testing) for clinicians.

Continuous Quality Improvement

- Assess the quality of initial data collected onto the CYANS Allergy Database and review data fields accordingly.
- Set up clinical audit templates for use in the long term to evaluate and monitor the efficacy of data collected against core quality indicators and current best practice and guidelines
- Provide robust data to provide baseline to audit service provision for allergy
- Develop new data fields and additional coding to adapt the allergy database for the collection of data on severe food allergy, as well as the development of Care Quality Indicators for food allergy.

Involvement of service users and their families

- Continue to collaborate with children, young people and their families to meaningfully evaluate the success of CYANS' recommendations from the service users' point of view.
- Develop a method of capturing information on service users' experience of allergy care in Scotland towards the end of the initial implementation phase, and evaluate results against current research and findings.

The CYANS Allergy Advisor will have the necessary skills and competencies required to lead and coordinate the implementation work outlined above including clinical knowledge and experience, research skills and time. The agreed implementation workload would not be achievable within a part time (0.5 wte) post and warrants a fulltime position. It is the view of the steering group that the full time support of the Allergy Advisor post for one more year will enable CYANS to become a fully established NMCN and be sustainable beyond 2014 with the support of a network manager.

4.3 Cost implications of the funding recommendations

CYANS Lead clinician backfill 2 sessions	£ 23,400	recurrent
CYANS Administrator 0.5	£ 11, 720	recurrent
Supplies and overheads (The collective NMCN budget is shared by 4 networks in Lothian NMCN office to ensure the most effective utilisation of resources.)	£11,500	recurrent
CYANS Allergy Advisor 1 wte (July 2013 - June 2014)	£ 42,000	
CYANS Network manager 0.5 wte (June 2014 ongoing)	£ 21,000	recurrent

5 Conclusion

Recommendations

In conclusion, to have the desired effects and improve allergy service provision for children and young people in Scotland, CYANS will require funding in the longer term beyond the initial project phase and support to become a fully fledged National MCN. To enable an initial implementation of the recommendations, continued funding of the allergy advisor position until June 2014, is essential.

With the approval of its steering group and clinical lead CYANS therefore proposes continued funding for the allergy advisor at current levels for one further year (July 2013 – June 2014) and funding for a network manager at 0.5 wte thereafter.

Appendices

Appendix table 1

CYANS Achievements June 2011 – November 2012

CYANS has,

- Established itself as a National MCN with a membership of 590 contacts across Scotland including young people and parents, voluntary organisations, academic researchers, health care planners and health care professionals from across a range of clinical specialties, primary and secondary care.
- Established a network governance framework with steering committee, working group leads, work streams, and work timelines.
- Established contacts for professionals and parents / carers of children and young people with allergies to ensure that stakeholders are identified and are engaged effectively in the establishment and ongoing development of the network.
- Agreed a communication strategy to effectively engage CYANS stakeholders.
- Formally launched the network in March 2012, attended by 64 delegates from across Scotland.
- Designed, developed and launched a website to aid communication and engage service users.
- Designed and circulated newsletters to aid communication and engage service users.
- Devised an allergy database based on the Clinical Audit System and identified anaphylaxis as the clinical condition appropriate for initial data collection.
- Defined quality and performance indicators for anaphylaxis management.
- Developed and agreed on recommendations and clinical pathways for the clinical management of anaphylaxis.
- Developed draft recommendations and clinical pathways for the clinical management of food allergy. .
- Completed a scoping exercise to map current allergy services in Scotland.
- Completed and analysed a scoping exercise to identify education and training needs of health care professionals in paediatric allergy.
- Developed a draft education strategy.
- Assessed and identified suitable allergy education packages.
- Produced an annual report to document achievements to date and objectives for the year to come.

Appendix table 2**CYANS - projected work plan December 2012 - June 2013**

Action	Outcome	Date
Complete work group tasks	Provide recommendations for allergy care	Dec 2012 / Jan 2013
Update website and circulate newsletters	Maintain communication and engagement with CYANS stakeholders	Ongoing
Prepare Clinical audit system for use	Begin data collection and carry out initial audits	June 2013
Review existing guidelines and standards for food allergy	Develop recommendations for food allergy	January 2013
Develop an educational strategy	Recommend training solutions for clinicians	January 2013
Develop and deliver an educational pilot for primary care clinicians	Training in allergy for Primary care clinicians	Spring 2013
Continue to involve service users	Provide a report for service users	Spring 2013
Develop transition pathway for young people to adult services	Provide a clear pathway of care for young people to adult services	June 2013
Allergy Advisor to write final report	Provide Scottish Government with recommendations for future provision of allergy services	June 2013

Appendix 3
CYANS work plan for July 2013 – June 2014

Action	Outcome	Date
Develop and deliver road shows to health boards across Scotland to assist with implementation of recommendations	Improved allergy service provision for patients and families Clear referral pathways and pathways of care	Ongoing throughout 2013/ 2014
Evaluate efficacy of education pilot for primary care based on results of the allergy education pilot	Development of an allergy education and training programme for clinicians in primary care	June - Sept 2013
Delivery of allergy education for primary care	Allergy training for primary care clinicians available locally in all health boards	Oct 2013 - June 2014
Develop, monitor and evaluate mentor support for clinicians	Education and support made available to clinicians as locally as possible	Ongoing throughout 2013 /14
Develop, monitor and evaluate clinical allergy support network	Clinicians will be empowered to provide high quality allergy care locally.	Ongoing throughout 2013 /14
Organise and deliver service users workshops across Scotland	Service users can feedback to CYANS the impact of work on service provision accessed	Spring 2014
Audit and evaluate data collected on CYANS - Allergy database and develop clinically relevant audit tools for quality improvement	To provide valid baseline data of allergy service provision in Scotland to enable audit of service provision for allergy	Ongoing throughout 2013/ 14
Develop CYANS - Allergy database to collect information on food allergy	Effective method of data collection on food allergy and provision of base line data for Scotland	Data collection from November 2013, initial audit estimated May/June 2014
Develop practical resource package for food allergy	Resource will equip all primary care clinicians and general paediatricians with resources to treat and manage straightforward food allergy.	Throughout 2013/14

Appendix 4

CYANS Care Quality Indicators for Anaphylaxis

- % of children and young people with suspected or confirmed anaphylaxis that have been referred for specialist assessment.
- % of children and young people with suspected or confirmed anaphylaxis that have had a diagnosis confirmed or refuted.
- % of children and young people with suspected or confirmed anaphylaxis that have had triggers identified.
- % of children and young people who have been prescribed an adrenaline auto injector at the correct dose.
- % of children and young people diagnosed with confirmed or suspected anaphylaxis that are reviewed annually by a specialist clinician.
- % of children & young people who have been given a management plan on discharge after a suspected anaphylaxis event.