

# **Visual Impairment Network for Children & Young People (VINCYP)**

## **Annual Report**

### **2023/24**

**Lead Clinician:** Dr Margot Campbell  
**Programme Manager:** Hazel Johnstone  
**Programme Support Officer:** Chris Williamson

## **Introduction**

The Visual Impairment Network for Children and Young People (VINCYP) was established in 2014 with the aim to improve the care for children and young people with a visual impairment.

The definition of Visual Impairment (VINCYP Criteria) is:

- Best corrected visual acuity (both eyes open) equal to or worse than 6/18 or 0.5 logmar
- Requires N18 print or larger to read comfortably
- Visual field loss with both eyes open which significantly affects function
- Any eye movement disorder which significantly affects visual function
- Any form of cognitive visual dysfunction due to disorders of the brain which can be demonstrated to significantly affect function

Since its inception, VINCYP has developed and rolled-out the VINCYP Standards, Quality Indicators and the Pathway of Care, that support early identification and early referral to appropriate community services along with consistent and evidence driven approach to investigation.

The network also captures information on the number of children with a VI in Scotland via an online database, Clinical Audit System (CAS). This information is available to support Scottish Government, health boards and local authorities to show the prevalence of childhood VI in Scotland and is used to improve service and financial planning in addition to supporting research.

The network has a strong education focus for all groups of professionals providing services to children and young people with visual impairment. The aim is to improve pathways of care, provide full and accurate assessment, particularly for children and young people with suspected cerebral visual impairment, and to build confidence amongst service providers. The Network also provides information for parents and children and young people with visual impairment in collaboration with others.

The work of the network is carried out through collaborative working with professionals working in health, education and social work, parents/carers of children and young people with a visual impairment, and voluntary sector organisations.

## **Current Position**

The network has benefited from the continuation of clinical expertise and leadership provided by the Lead Clinician (LC), Dr Margot Campbell, since 2017. Dr Campbells' tenure ended 31 March 2024.

The network has successfully delivered various projects against its objectives through four established subgroups (Education, Data, Services & Standards and Family Engagement) and supported by the Steering Group (SG), chaired by the LC.

The network achieved 21/22 (95%) of its service delivery objectives in 2023/24.

Plans to deliver and evaluate a pilot regional training session to a multi-disciplinary group of professionals to support and develop their understanding of the VINCYP pathway were not completed during this period. This has been carried over into 2024/25.

## Highlights

During 2023/24 the network has successfully undertaken various projects with highlights detailed below:

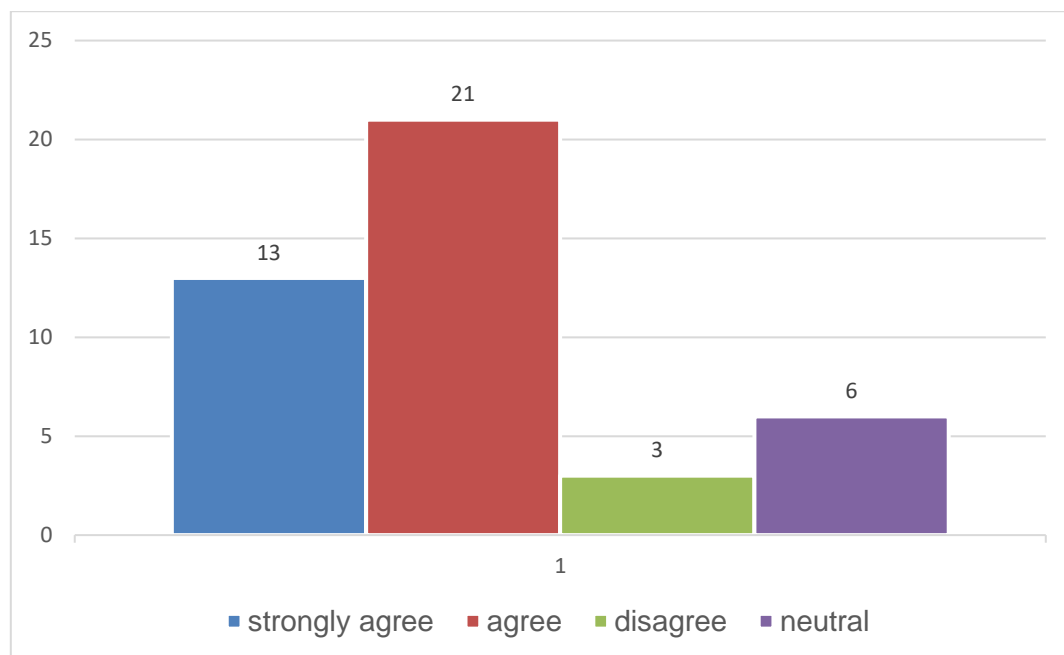
### Education Training Day

In November 2023, 49 Allied Healthcare Professionals (AHP) attended a training day 'Supporting Babies & Young Children with VI & Complex Additional Support Needs'.

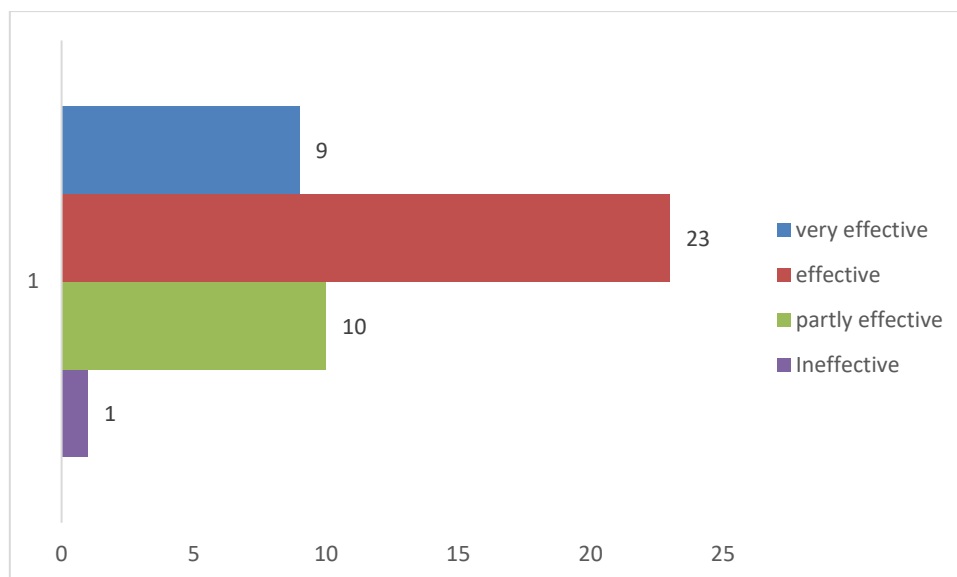
This event was arranged following demand from a similar training day delivered in September 2022 to qualified teachers of Visual Impairment (QTVI) and Habilitation Specialists in 2022. It was aimed at and attended by Speech and Language Therapists, Occupational Therapists and Physiotherapists.

The positive results of this education event were a testament to the hard work of the presenters and is evidenced by the following highlights:

**79%** of respondents **agreed** or **strongly agreed** the objective of the day had been met.



**74%** of respondents rated the extent to which their learning from the event will change their practice as '**very effective**' or **effective**'.



### Mentoring Programme

A short life working group was established to consider alternative ways of how the VINCYP mentoring course can be delivered in future. The mentoring course was previously arranged for orthoptists and paediatricians following the specialist training course as part of a funded programme by Scottish Government. This was delivered by the Scottish Sensory Centre (SSC) on behalf of VINCYP; however, this is not currently being offered due to the lack of mentors. The SLWG was formed to find out:

- if there is a need for the mentoring programme
- if there are paediatricians and orthoptists who would be willing to be mentors
- how this programme would best be delivered for it to be accessible to busy professionals

### Paediatrician responses

There were eight responses to the survey from **paediatricians**. The results have shown 4 out of 8 are interested in being a **mentee**. However, there is only one paediatrician willing to be a **mentor**. Four paediatricians have responded that although they cannot commit to a full mentoring role, they could undertake **some** mentoring duties.

The responses have shown that the interested **mentees** would prefer formal face to face meetings with a mentor, approximately three times per year. They would also be willing to participate in some research, planned tutorials. These are generally supported by the **mentor** responses.

### Orthoptists responses

There were six responses to the survey from **orthoptists**. The results have shown that **all** orthoptists are, or possibly interested in being a **mentee** for such a programme. There were no orthoptists who have agreed to commit to a full **mentoring role**; however, four orthoptists have indicated they could undertake some aspects of mentoring duties.

Similar to the paediatrician responses, the interested orthoptists mentees have indicated they would prefer formal face to face meetings, three times per year. However, the mentors have indicated they could not commit to this frequency. This will require to be explored further to understand if any compromises can be reached.

The next steps to explore further how this can be delivered have been paused due to the lack of clinical leadership, however, is expected to be reviewed as part of the 2024/25 workplan activity.

### **VINCYP Course- An Introduction to Childhood Visual Impairment**

Members from the core team engaged with staff from the University of Edinburgh Scottish Sensory Service (SSC) to review previous resources and plan delivery of the Introduction to childhood visual impairment course to education and health care professionals. An initial audit of the resources and speakers was completed to determine any gaps in resources. It was identified that three professional speakers have since retired, therefore further engagement will be required to confirm how these can be delivered. VINCYP received funding in 2019 to deliver a programme of training courses in collaboration with the SSC and there is sufficient funding available to continue this programme. The delivery of this course will be considered further as part of the 2024/25 workplan activities.

### **Audit and Continuous Quality Improvement**

The network continues to use the Clinical Audit System as a national database to record patient information and disseminates information on a quarterly basis (Highlight Reports) to individual health boards.

Data collated in CAS is also used to generate transition letters that are issued to children when they reach 15½ years to inform them about the adult sight impairment registration process. The network has issued 120 transition letters during 2023/24 and is able to provide data to Scottish Government as required.

### **Short Life Working Groups**

Members of VINCYP have supported various short life working groups throughout 2023/24. Key outcomes from these SLWG's include:

The development of a 'A model for provision of eye care in special schools/additional support need schools in Scotland'. Dr Margot Campbell and Professor John Ravenscroft presented the need for this provision to the Cross-Party Parliamentary Group for Visual Impairment on 20 September 2023. Stuart McMillan, MSP has confirmed the support of the Cross-Party Group to further explore the potential benefits of introducing this model across Scotland. Engagement is on-going with Scottish Government colleagues to agree the appropriate next steps.

Further to the publication of the National Ophthalmic Workforce Review (NOWR) document published in January 2024, VINCYP prepared an SBAR on behalf of NHS Scotland to highlight the challenges occurring in paediatric ophthalmology services in Scotland; particularly the ongoing problems with recruitment and staffing levels, which are impacting service standards nationally.

VINCYP has engaged with Scottish Government and colleagues from the Centre for Sustainable Development (CfSD) and are exploring how they can collaborate to agree the next steps.

The VINCYP pathway of care was originally developed in 2015 and has been implemented variably across Scotland. It was agreed to establish a SLWG to review the pathway. The only change identified was to clarify the involvement of third sector organisations who provide social care services. An accessible version of the pathway has also been developed along with a supporting document to further explain the pathway and align this to Scottish Government's Getting It Right For Every Child ([GIRFEC](#)) principles. Once these have been approved by steering group members, these will be promoted through engagement with various stakeholders and publication on the VINCYP website. A questionnaire will be designed during 2024/25 to audit compliance and confidence in the use of the pathway. The output from this may inform any future training requirements.

## **Stakeholder Engagement**

### **Meeting with the Heads of Sensory Services**

In September 2023, Dr Margot Campbell presented the VINCYP pathway and standards at the meeting of the Heads of Sensory Services in Education. They are the managers of both the Visual Impairment and Hearing Impairment teachers. Feedback from the group included the following "VINCYP is one of the real strengths in current VI education".

"In Local Authorities where VINCYP is working well, there is invaluable information sharing that happens in clinics. When QTVIs and paediatricians are working together there is a much better approach to assessment, and appropriate recommendations, and strategies from that assessment too."

The other added value VINCYP brings is the training days and courses, and the feed back from the number of respondents agreeing that their practice has been influenced or consolidated by attending the event.

### **Stakeholder Survey**

A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the network. The survey was shared 82 stakeholders, and 20 responses were received (24% response rate).

While the number of responses was disappointing, a lot of positive feedback was received and highlights the value added by the network:

- **80%** responses 'strongly agreed' or 'agreed' that the network provided a structure to make service improvements in CYP VI care.
- **100%** responses 'strongly agreed' or 'agreed' that the networks service development activity adds value to CYP VI care.
- **75%** responses 'strongly agreed' or 'agreed' that the networks education offering adds value to CYP VI care.
- **70%** responses 'strongly agreed' or 'agreed' that the networks audit and continuous quality improvement activity adds value to CYP VI care.

The survey was also an opportunity for stakeholders to share feedback on network strengths, network challenges, areas for improvement and the priorities for the next few years. The responses are summarised below:

<b>Strengths</b>	<b>Areas for Improvement</b>
<ul style="list-style-type: none"> <li>• Common language between all professionals supporting the child.</li> <li>• Being able to identify weaknesses in provision at a national level and then being able to actively address these weaknesses.</li> <li>• Provision of high-quality learning for a wide variety of practitioners.</li> <li>• Bringing together people who are involved in the same industry but rarely communicate effectively together.</li> <li>• Good way to document visual impairment and consent to share information.</li> <li>• Collaborative cross sector working</li> <li>• Highlighting all children with a visual impairment and having them all in one place.</li> <li>• Clear and connected pathway to ease support for families and connect multi-agency working.</li> <li>• Admin team are very efficient.</li> </ul>	<ul style="list-style-type: none"> <li>• The network needs to grow from the strong base which it has. It needs to continue to engage with young people and their families as well as stakeholders widely.</li> <li>• Its meagre resources should be substantially increased reflecting the potential of visually impaired children and young people.</li> <li>• Government should recognise that Habilitation services should be a statutory requirement for visually impaired children and young people.</li> <li>• Streamline the data points that are to be collected as filling in the form takes a lot of time</li> <li>• I would like to see further collaborations across the network with new and existing stakeholders</li> </ul>
<b>Suggested Future Priorities (3-5 years)</b>	<b>Network Challenges/Threats</b>
<ul style="list-style-type: none"> <li>• Continue to promote collaborative working across health, education and third sector to improve outcome for children and young people and their families.</li> <li>• Develop equality of service across all Health Boards and ensure that data is captured accurately.</li> <li>• Continue to provide high quality learning opportunities across all disciplines - health, education and third sector.</li> <li>• To network more including grassroots e.g. people who are working on the ground day to day with children and young people should have more opportunities to interact with all agencies.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of money! If all learning is to be online, then this does not foster collaborative working in its true sense. The online experience does not facilitate this. I can understand committee meetings and steering groups being online but not every aspect of training. Additionally, undertaking the lead clinician or chairing a committee takes up a lot of time. Not everyone has this time and not all employers support this. My concern is definitely around succession planning. Finally, I think the network has become very paper driven and while I fully understand the need to be transparent in what we do, I think procedures could be</li> </ul>



<ul style="list-style-type: none"> <li>• Vincyp should have a higher profile in the visual impairment community.</li> <li>• Develop core data set drop down boxes as I am often unsure how to fill in information consistently and there are a large number of points which do not seem to be in use.</li> </ul>	<ul style="list-style-type: none"> <li>streamlined in order to remove some pressure from admin staff.</li> <li>• Erosion of clarity of objectives and an inability for government to see the potential of children/young people who live with a severe visual impairment.</li> <li>• Time taken to input data.</li> <li>• Resource.</li> <li>• Broadening who the network work with to deliver outcomes could be a supportive way of widening the circle of reach.</li> <li>• Lack of professionals supporting the network.</li> </ul>
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The feedback received will be considered by the VINCYP Steering Group and an action plan to support areas for improvement will be developed.

The Network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate friendly practices.

## Looking forward – 2024/25

The network has identified key priorities:

- develop an action plan for improvement to support equity of service and/or improved patient outcomes
- explore the impact and benefit of developing a process to ensure consistent sharing of information regarding the number and type of VI for CYP within each local authority area
- consider feedback to identify any next steps required around shortage of paediatric ophthalmologists
- consider feedback to identify any next steps required around eye care in special schools
- promote the use of the updated VINCYP pathway through piloting a multi-disciplinary training session and through professional groups
- contribute to Guide Dogs Scotland project to review and develop transition resources by providing subject matter expertise
- create a directory of paediatric low vision clinic services available

## Finance

During the reporting period, the network spent £972.80 of its £5000 budget during 2023/24. This was spent to host the 'Supporting Children and Babies with VI and Complex Needs Education Event Day in November 2023.



## **Risks & Issues**

The network is currently without dedicated clinical leadership which may impact the delivery of the network's business plan.

Due to the current financial constraints within NHS Scotland, networks have been asked to hold events virtually to reduce costs to local NHS Boards for staff travel. VINCYP members value the opportunity network events offer to meet with staff from across services supporting CYP with VI and have requested an in-person education event to collaborate effectively. Should the events take place virtually network members feel they would be of limited value, offer little return from a networking perspective and therefore attendance may be greatly impacted.

## Appendix 1 – Clinical Audit System (CAS) User Engagement

The number of patients recorded in the CAS system in 2023/24 is 695 as shown in diagram 1 below. This shows 386 patients recorded as “new” during this period that will have been entered when first seen in clinic. The remaining 309 patients recorded as “review” may not have been entered onto CAS when first seen, so these have been added when seen as part of a review appointment.

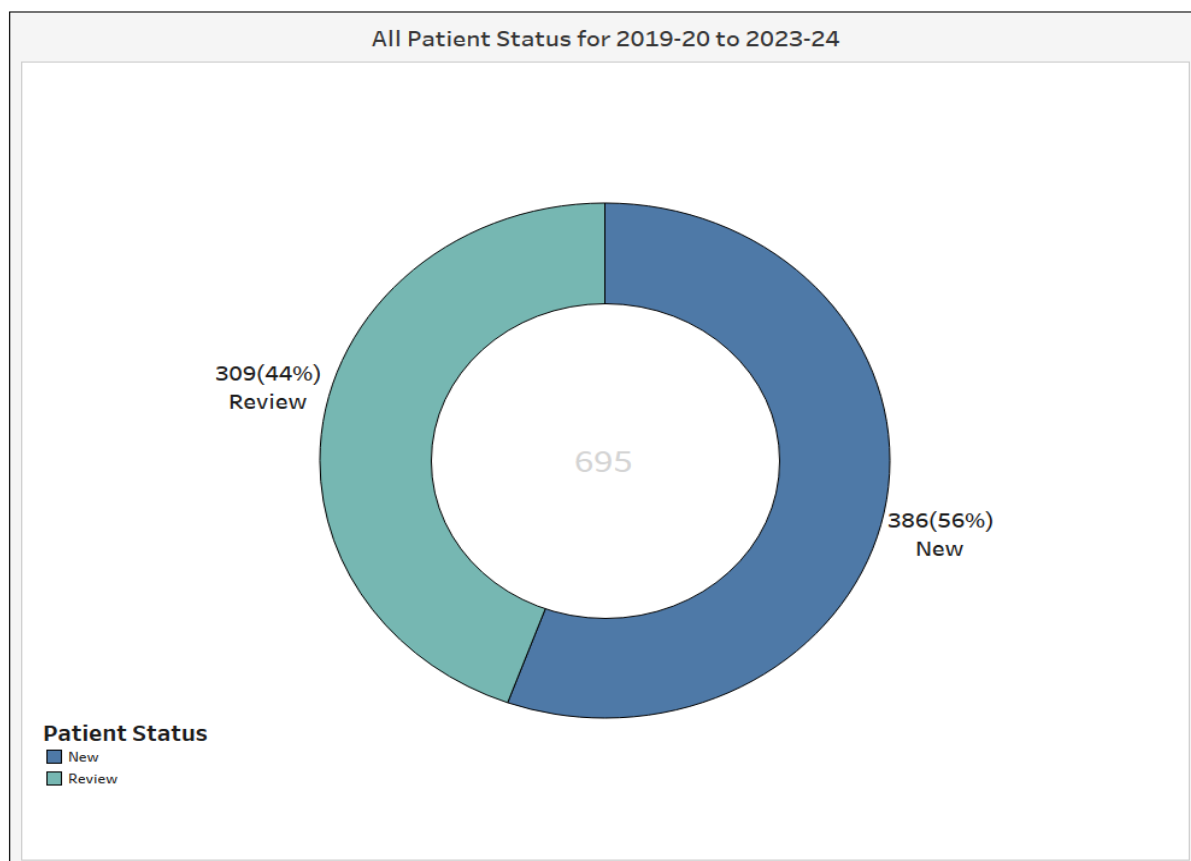


Diagram 1 – All patient status

Based on the CAS 2023/24 data recorded, diagram 2 below shows the age range of all VINCYP patients, with the average age of patients recorded as age 11:

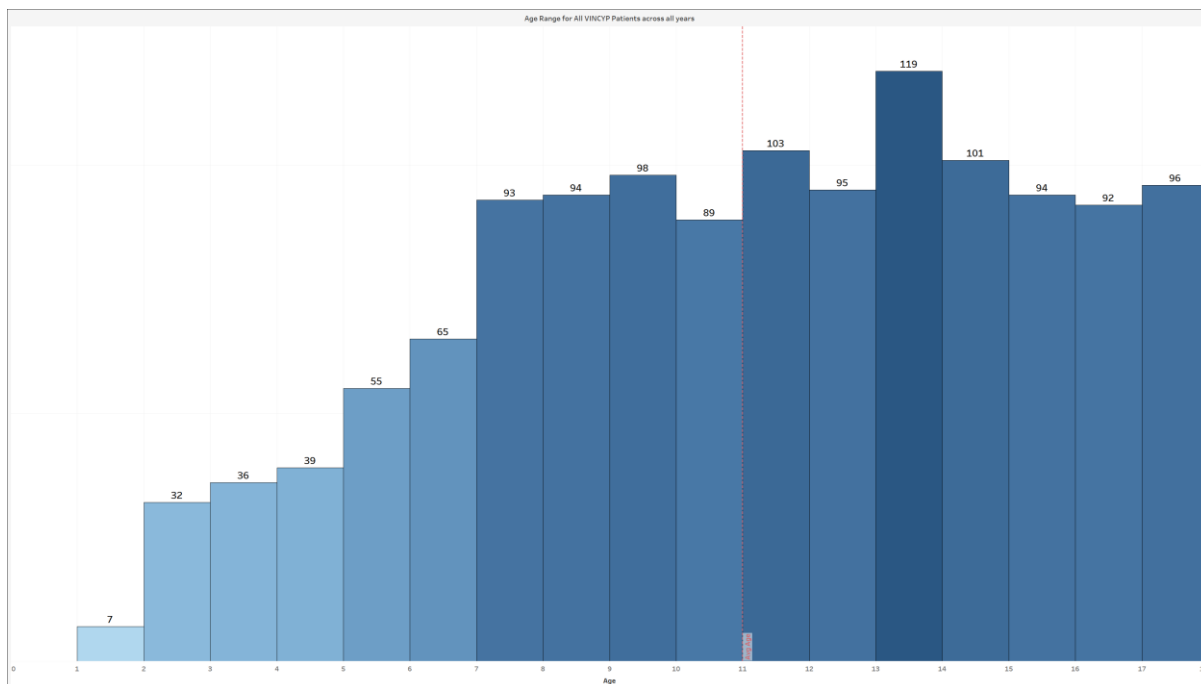


Diagram 2 – Age range for all VINCYP patients across all years

Diagram 3 below shows the number of all patients recorded by health board regions recorded on the CAS system during 2023/24.

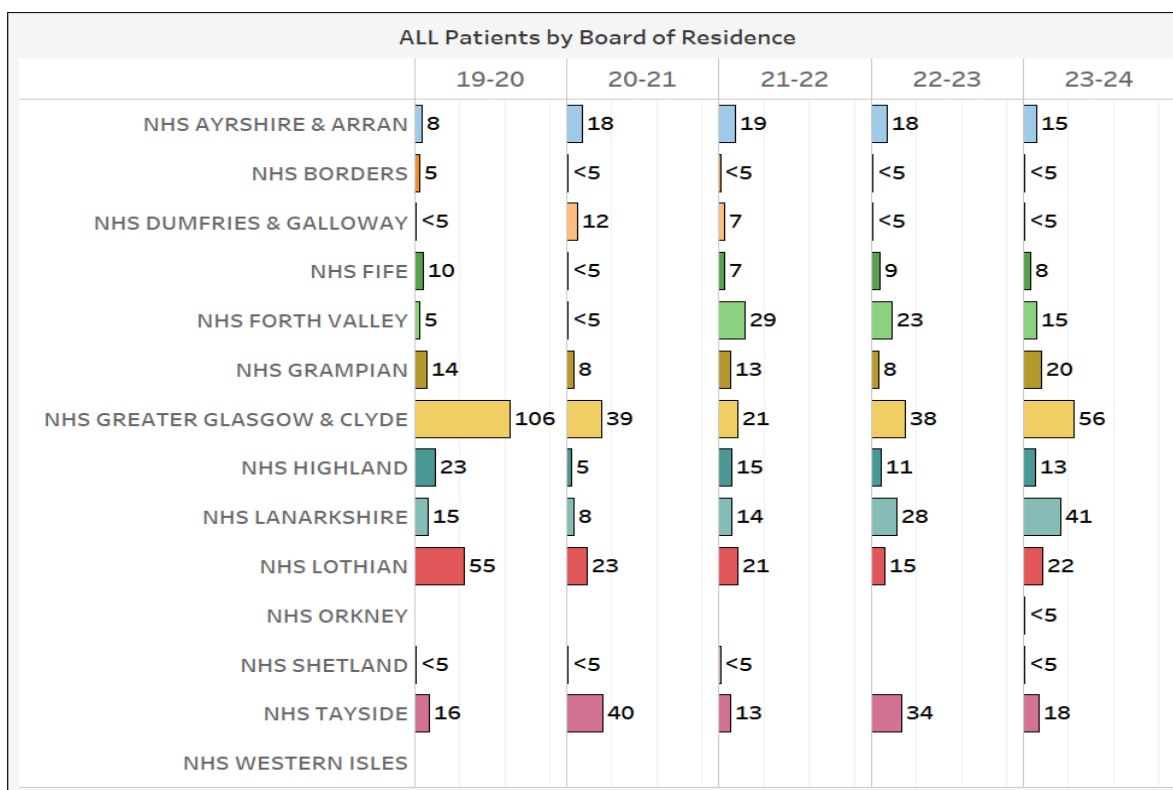


Diagram 3 – All patients recorded by health board

Quality Indicators relating to the VINCYP standards have been agreed to evaluate the effectiveness of the patient's journey using CAS data. The KPI report below (Diagram 4) shows five years' data. This allows the network to analyse past performance and provide an opportunity to see any gaps in the data.

Diagram 4 below also indicates the data for many patients is incomplete. This was discussed with the data subgroup, and it is acknowledged that the process for receiving this information from the various services back to health board staff to update CAS is not being followed. These KPI's were deemed as still important, therefore, it is the mechanism to collect this information and update CAS that needs to be improved. This will be discussed at the next Steering Group meeting.

The network is able to report that ~57% of children are seen in a dedicated children's clinic.

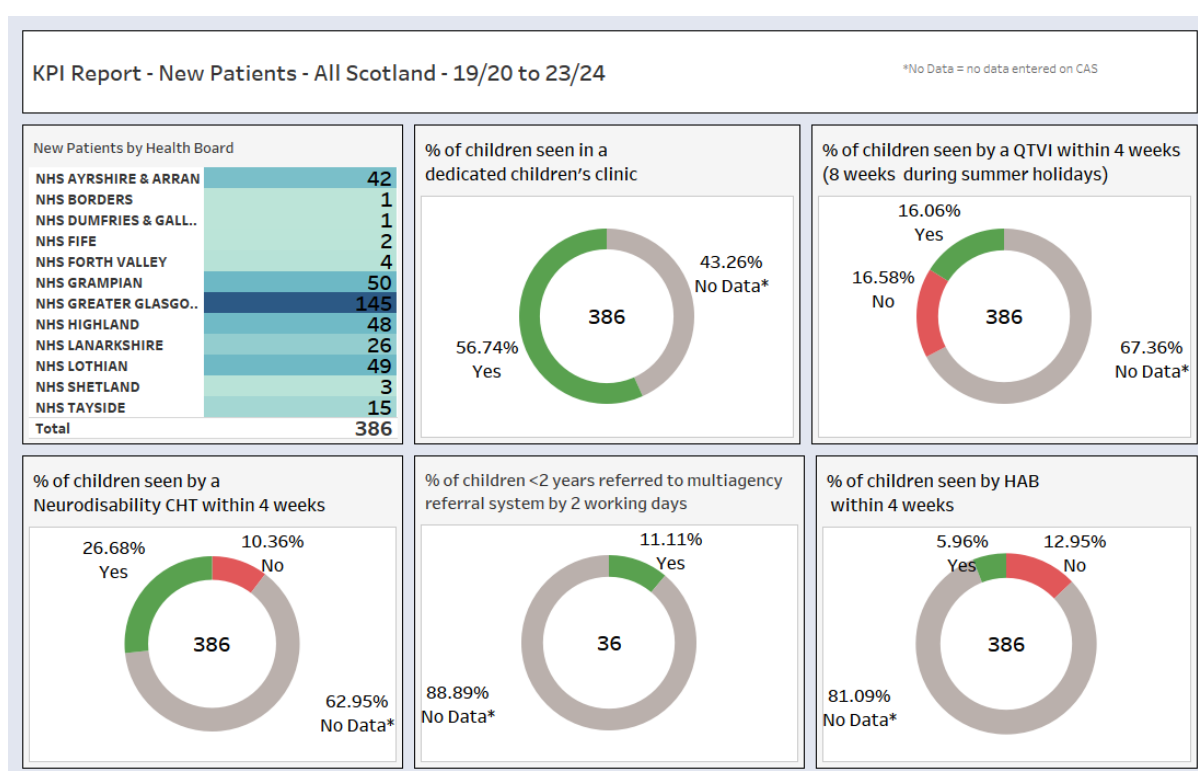


Diagram 4 – All patients recorded by health board