"Let's see if we can help"
The development of a resource for health and social care professionals to
assist people with a vision impairment manage their medicines

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SECTION 1. INTRODUCTION

In 2010, the number of people registered as blind or partially sighted in Scotland was estimated to be 34,492, and of these 75% were over the age of 65[1]. However, registration is voluntary, and research in 2001 suggested that for every person registered, there was likely to be another two people who meet the criteria but are not registered[1]. With age comes the increasing likelihood of morbidity with almost 40% of over 75s likely to have two or more long-term conditions[2]. As a result, this population is likely to be subject to poly-pharmacy with its associated risks[3]. It has long been recognised that problems with taking medicines correctly can result in admission to hospital, and that a proportion of these admissions are potentially preventable. There are two main reasons why patients fail to take their medications as prescribed:

- the person has chosen not to (intentional non-adherence), or
- the person has practical problems in taking their medications (unintentional non-adherence)[4].

In order to help minimise unintentional non-adherence it is necessary to:

- identify the correct medication,
- have clear information about how it should be taken and in what quantity, and

- understand specific barriers the person has to overcome and any particular challenges the person has.

The vast majority of medicines are packaged in rectangular cardboard cartons or brown medicine bottles of varying sizes, and normally come with a patient information leaflet (PIL). For a person with a visual impairment, differentiating between their various medicine containers can be very problematic. This is particularly so if the packaging is not a distinctive colour, nor identified by distinctive labelling i.e. something more than just the label added by the community pharmacist.

This has been recognised and an EC directive (2001/83/EC) was issued which, amongst other things, required all medicines (except injectables given by healthcare professionals) to have the name of the medicine embossed in Braille on the carton or immediate packaging from 30th October 2005. However, only a small proportion of vision impaired people can read Braille and over time, other methods of identification have been developed - most usually by individuals and/or carers and/or community pharmacists.

In October 2009 West Dunbartonshire CHCP was approached by members of a local group, Focus, an umbrella organisation for vision impaired people (VIP) in West Dunbartonshire. Focus outlined some of the difficulties encountered by VIP the safe use of prescribed medications. These were concerns experienced by, and reported to, Focus. An example was a local resident who was concerned that pharmacy dispensing labels were being placed over the Braille by his pharmacy[a]. This prompted an awareness raising campaign, supported with training from Visibility[b], amongst the local community pharmacies about the problems faced by people with a vision impairment. This led to general discussion about the methods used by this population to identify medicines, and how this could be shared with a wider community. This discussion resulted in the idea of producing a resource that would enable pharmacists amongst other professionals to help this vulnerable group of patients to use and take their medicines safely.

A steering group of NHS staff; West Dunbartonshire Council (WDC) staff; voluntary sector organisations; service users; pharmacy contractors; and optometry contractors was brought together to develop the proposed resource.(Appendices 1 and 2)

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[a] It should be noted that the resident had also commented on this to the pharmacist, and been delighted with the pharmacist's positive reaction to his feedback, and the actions subsequently taken by the CHCP.
[b] Visibility is a voluntary sector organisation which supports people with a visual impairment to make their own choices and live their lives fully, confidently and independently.

SECTION 2.   AIMS AND OBJECTIVES

The purpose of the steering group was to explore the medication-related communication difficulties experienced by all residents of West Dunbartonshire, with an initial emphasis on residents with a vision impairment, including those with learning disabilities, and to support and advise care staff working towards improving the services they provide.

Its aim was to:
- improve the medication-related experience of vision impaired residents of West Dunbartonshire;

and its objectives were to:
- develop a resource - "hints and tips" for health and care staff to help patients or service users to use and take their medicines safely,
- pilot and evaluate this in West Dunbartonshire, initially with local community pharmacies.
- consider whether and how the resource should be rolled out across NHS Greater Glasgow and Clyde, and
- form short-life working groups or "task and finish" groups to address the associated work streams.

SECTION 3. PROCESS

Following the initial meeting of the steering group in Spring 2010, a Weaver's Triangle (Appendix 3) was prepared and this summarised the activities that would be undertaken to complete the project:
- Undertaking a scoping exercise to better understand what is currently available and the current ways that people may identify and label medicines.

- Undertaking a brief gap analysis to identify unmet need for specific resources.
- Obtaining materials from external sources as appropriate.
- Developing materials as needed.
- Devising a communication plan for the project.
- Devising an evaluation strategy for the project.
- Developing supporting materials for training and education.

In addition, a work plan (Appendix 4) was agreed, which included the formation of "task and finish" groups.

During the period from early summer 2010 to early 2011, the individual groups undertook their tasks and reported back to the main steering group. In spring 2011, the development sub-group drafted the resource itself. This has two elements:

- a written guide of "hints and tips", with sections on ways to help people take their medicines, labelling and identification of medicines, and links to further information; and
- a pack containing samples of stickers, pictograms to help identification of medicines and assist with directions, and aids such as bump-ons, together with information about stockists.

Funding for design and printing was identified through the NHS GG & C Corporate Inequalities Team.

The resource was launched at a meeting for community pharmacists in April 2011.

The following table summarises the work of the various groups.

	Group	Task	Output
1	Gap Analysis	Explore areas with which patients and service users have difficulty with taking medication, and gather information about the methods they use currently	Work undertaken with various groups to identify gaps and current tools, and brief report prepared
2	Good practice	Identify currently available aids and good practice	Literature search undertaken and current tools explored with partner agencies and services
3	Development group	Agree content and prepare content of resource	Resource produced as guide and pack together with poster materials
4	Communications group	Devise a communication plan for the launch of the resource	Launch event planned and publicised
5	Training and education group	Identify needs re training and education and recommend how best they can be met	Role superseded by planned availability of intranet based learning materials, and by work of Group 3.
6	Evaluation group	Devise and implement an evaluation strategy for the project	Evaluation plan and data capture tools devised and implemented

A timeline of project activity is presented below

Date	Activity	Finish
April 2010	First meeting of steering group Identification of Task and Finish Groups	
July 2010	Literature search undertaken	August 2010
September 2010	Gap analysis undertaken	January 2011
January 2011	Resource and poster developed	March 2011
March 2011	Evaluation plan devised for resource	March 2011
April 2011	Resource and poster printed Resource and poster launched	April 2011
May 2011	Baseline info gathered re pharmacies	May 2011
November 2011	Press release issued	November 2011
January 2012	Patient experience information sought – visits to ophthalmology out-patients at Vale of Leven Hospital	Jan 2012
February 2012	Final evaluation data gathered from pharmacies	Planned March 2012
March 2012	First draft of project report prepared	

SECTION 4. REVIEW OF OUTCOMES

As described earlier in this report, the purpose of the project was to explore medication related difficulties experienced by people with low vision, and to develop a resource that would help to address these.

A range of evaluation activities was undertaken to enable an assessment to be made of the process used to progress the work and of the value of the resource.

Process

During the early stages of the work, all steering group members were asked to comment on the structure and content of meetings. Feedback included:
- "I have found it helpful that the meetings are arranged well in advance and the papers circulated beforehand."
- "It is good that there is a wide range of skill / knowledge / experience in the room, as well as different professional backgrounds."
- "The task and finish groups (a new terminology for me) have been instituted and are reporting back to the wider group, which helps with understanding how the work streams fit together."
- "It can be challenging to contribute to the discussion in such a sizeable group."
- "I think it is really useful when we go into the sub-groups because it is easier to speak out with a smaller group of people."
- "I enjoy the subgroups because it gives me a clear focus of what my role is."
- "Good chairing of the group enabling us to keep focused on the tasks."
- "Work plan really helps to keep us focused (even though deadlines are not set in stone)."
- "Recapping and re-visiting issues during the meeting really helps clarify things for the whole group."
- "I think its really good how everyone is listened to and all points of view taken on board (possibly again linked to good chairing)."

The resource - pharmacies

As regards the resource, baseline data on pharmacy activity in relation to low vision problems was collected in April and May 2011. It was felt that previous discussion of the project locally had already raised awareness of the problems

faced by people with a vision impairment, and therefore it was agreed that pharmacists working in a different CHCP should be surveyed, as proxies.

Of 16 pharmacists approached, three said that they do ask people about problems with their sight, but only if there is a clear indication that such a problem exists. For those who do not ask, reasons given included not having time; not feeling that there was anything they could offer should such a problem be acknowledged; and feeling that family, friends and carers are able to provide appropriate help. Of those who did ask, the help they subsequently offered related primarily to the size and positioning of labels.

The resource was distributed with a data capture form for completion each time the guide and/or pack was used. The form would provide information about how often the resource had been used; the difficulties that had been presented by the individual; and the extent to which the resource had enabled staff and the individual to identify a solution.

In addition, some months after the launch of the resource, pharmacists were asked about their use of the guide and pack – whether they had used it; whether either part of the resource had been helpful; whether discussion with the patient or carer had elicited solutions other than those suggested in the guide.

At the time of writing, 11 pharmacies had responded. Of these, 46% reported that they had found the guide useful, and described being able to explain to patients what is available; and some had used items from the pack, such as the morning and night stickers. Reasons for not using the pack included not having enough time, and not having had a need for it at that time. There were no reports of further suggestions or ideas for ways to take medicines safely.

The resource – patients
The steering group was also concerned to gather views of individuals with a vision impairment so as to assess its impact for them.

Work undertaken as part of the gap analysis included visiting the ophthalmology out-patient clinic at Gartnavel General Hospital, and asking patients about their use of pharmacy services, and whether enquiry was ever made about the impact of their sight loss on the way that they take their medicines. A discussion was

also held with members of Focus, a local organisation for vision impaired people in West Dunbartonshire.

It proved difficult to access people who felt that they had a difficulty in taking their medication as a result of their sight loss, and no-one described pharmacists having made enquiry about how they manage.

Some nine months following the launch of the resource, visits were made to the ophthalmology out-patient clinic at the Vale of Leven hospital to ask local patients about any experience they might have had with the resource. Once again, it did not prove possible to find people who felt their sight caused a problem as regards taking their medication, though one person reported having been asked about this by their pharmacist. Whilst people did comment that they felt their pharmacists to be approachable and understanding, it was also common for people to have their medications delivered, thus limiting direct contact. A number of people said that they would talk to their GP about any medication issues. There is anecdotal evidence from the Sensory Impairment Service that pharmacy staff have raised the issue with individuals, and changed their practice in ways such as marking boxes, and preparing eye drop bottles for immediate use.

It is perhaps worthy of note that informal discussion of the resource with other care staff was consistently met with interest and a wish to see a copy of the guide.

SECTION 5: DISCUSSION

The process

Reflecting on the process followed by the steering group, it is clear that many aspects worked well.

- Group meetings were run in such a way as to enable discussion and debate and were action driven.
- This was further enabled by the make-up of the group, which was both multi-agency and multi-disciplinary, and included involvement of vision impaired service users.

- The use of "task and finish" groups helped to clarify for people their role in the process, and identifying appropriate members for each was informed and facilitated by the wide ranging membership of the main steering group.
- The process of developing the resource resulted in the raising of awareness of the underlying issues amongst pharmacists and other care staff in the area. A number of local pharmacies were successfully engaged in the development of resource.
- The decision to undertake the project demonstrated reflection (and a willingness to follow-through) within the CHCP on the issues underlying a concern raised locally.
- Links were made and / or strengthened with a number of organisations – for example, a constructive dialogue developed with the RNIB as regards the compliance aids they offer through their catalogue.
- The work of the project provides a positive example of engagement with vision impaired people.

None the less, the progression of the project was not without challenges:

- Whilst the aim of the project was to address communication-related difficulties with medication, working to an agreed timescale resulted in an emphasis on vision impairment, and as a result there remains significant potential to support improvements for people who have a learning disability.
- Achieving the necessary and beneficial involvement of two large organisations – NHS GG & C and West Dunbartonshire Council – was complex. For example, the process of agreeing and issuing a press release about the resource was lengthy and time-consuming.
- Individual members of the group faced specific challenges in relation to the time and workload pressures under which they were working.

The use of "task and finish" groups
As an example of the "task and finish" group, the work of the gap analysis sub-group is summarised in a narrative of its process and a report on its outcomes at Appendices 5 and 6.

The production of the resource

As regards the production of the resource itself, it is worth noting that

- The steering group achieved what was planned and did so within a reasonable time frame.
- The publicity around the launch, including posters and press releases, raised awareness of the underlying issues in the local area.
- When the resource has been described to them, it has sparked considerable interest from care staff in other disciplines, settings and areas.
- The guide is available electronically and can therefore be shared widely at minimal cost. [It can be found by going to either www.wdchcp.org.uk/our-services/community-health-and-care/pharmacy-services/ or www.equalitiesinhealth.org/VisualImpairmentResource.html and an in each case clicking on the link provided.]

Equally, however, it is acknowledged that:

- Evaluation evidence suggests that the resource has not as yet been used as widely as had been hoped.
- Opportunities for publicising the resource and raising awareness of the issues – for example through links with optometry services - were not fully used.
- Dissemination of the resource itself initially only to community pharmacies may have diminished the extent to which it has been used.
- Finding people for whose circumstances the resource should have been helpful has proven very difficult, and as a consequence the patient impact aspect of the evaluation is extremely limited. (This is perhaps unsurprising given the context of generally helpful pharmacies and modest numbers of people with a significant vision impairment within which we were trying to track small changes.)

SECTION 6. CONCLUSION

The steering group (with its related task and finish groups) has successfully achieved its objectives of producing and disseminating a resource, comprising a guide and example pack, to support the safe use of medicines for people with

communication related difficulties particularly related to vision impairment. Through the production of the resource and its dissemination to local community pharmacies, awareness of the underlying issues has been raised. To date, use of the resource itself has not become embedded in practice and options for its further use and development are discussed in the next section.

SECTION 7. RECOMMENDATIONS AND NEXT STEPS

The steering group believes that their experience has resulted in useful learning that can be shared and used.

- Build (further) on the relationships that have been developed.
- Ensure that timelines within projects allow for the complexities of partnership working.
- The communication sub-group should continue as a Short Life Working Group to support the further dissemination of the resource, for example by:
  o members of the steering group being invited to continue to raise awareness of the issue in discussion with colleagues within their own and other organisations, through for example, the Older People Strategy Group,
  o tabling the final report on the project at the first available Clinical Governance Committee meeting within the CHCP,
  o establishing a link with the Facing the Future Together programme,
  o removing specific reference to West Dunbartonshire such that the resource is suitable for more general dissemination, including to management staff within pharmacy multiples,
  o ensuring the guide and information about obtaining consumables are readily available for download by hospital and community staff, including GPs and their teams, and the wider public on intra and internet sites of the organisations that have been involved in its development,
  o making the resource available to NHS Education for Scotland, and
  o considering how best to make the resource more available for staff in Learning Disabilities, and those working with people with literacy issues.

Finally, it is worth noting that the RNIB[5] suggests that as a result of the ageing profile of the population and of other health factors, the number of people with significant sight loss will double over the next twenty years – enabling the safe use of medication by this group is not a challenge that is going to fade away.

SECTION 8. REFERENCES

1. Registered Blind and Partially Sighted Persons, Scotland 2010. A National Statistics Publication for Scotland.
2. The Scottish Government. The Scottish Health Survey, Volume 1: Main Report (2009) http://scotland.gov.uk/Resource/Doc/325403/0104975.pdf
3. Hajjar ER, Cafiero AC, Hanlon JT. Polypharmacy in Elderly Patients. *Am J Geriatr Pharmacother* 2007; 5: 345-351
4. National Institute for Health and Clinical Excellence 2009 Medicines Adherence. Involving patients in decisions about prescribed medicines and supporting adherence. NCG76. London: National Institute for Health and Clinical Excellence.
5. The Cost of Blindness – Scotland 2010 – 2020. RNIB, Edinburgh, 2010

SECTION 9. APPENDICES

1	Terms of Reference – steering group
2	Membership of steering group
3	Weaver's Triangle
4	Workplan example
5	Gap analysis - narrative
6	Gap analysis - report

Visual Impairment Resource Development Steering Group
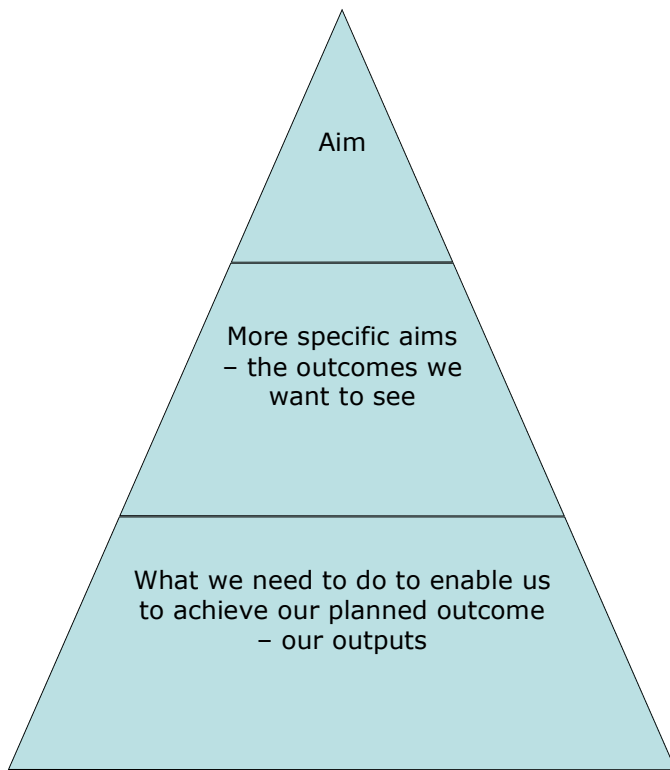
Terms of Reference September 2010

- The purpose of the group is to explore the medication-related communication difficulties experienced by all residents of West Dunbartonshire, with an initial emphasis on residents with a visual impairment, including those with learning disabilities, and to support and advise care staff working towards improving the services they provide.

- The group aims to improve the medication-related experience of visually impaired residents of West Dunbartonshire through the development of a resource pack, with the intention that this will be made available to care staff across NHS Greater Glasgow & Clyde.

- This work will be piloted in West Dunbartonshire with the expectation that it will be rolled out across Greater Glasgow and Clyde.

- Frequency of meetings: approximately every two months, more often if deemed appropriate.

- Meetings will be considered quorate when a minimum of eight group members are in attendance, with at least one person in attendance from NHSGG&C and FOCUS or VISIBILITY.

- The meetings will be minuted, and the work of associated workstreams undertaken by members of the group, eg via short-life working groups or "task and finish" groups, will be agreed by the group and will be forwarded to the Chair within an agreed timescale.

- The group will develop appropriate links with other colleagues and groups resulting in an improved medication-related experience for all residents of West Dunbartonshire & other areas who use NHS and associated services; it is envisaged that the learning resource produced by the group would be used as a basis for a similar tool to benefit others, eg vulnerable groups and those with multiple disabilities.

- Progress will be reviewed six-monthly and reported formally annually to the Joint Strategy Group for Sensory Impairment and the Corporate Inequalities Team via Wendy Jack and Jac Ross respectively.

Agreed September 2010

West Dunbartonshire CHCP

Visual Impairment Resource Development

Steering group membership

Name	Designation	Organisation	
Pamela Macintyre - Chair	Lead for Prescribing and Clinical Pharmacy, WD CHCP	NHS	
Margaret Black	Patient Involvement Facilitator, Clinical Governance Support Unit	NHS	
Norma Choat	Public Health Pharmacy Facilitator/Prescribing Support Pharmacist	NHS	
Mark Dickinson	Lead Community Pharmacist, WD CHCP	Lloyds Pharmacy	
Janis Howie	Senior L&E Advisor	NHS	From March 2011
Douglas Gilroy	Secretary	Focus	
Margaret Gilroy	Member	Focus	
Heather Harrison	Prescribing Support Pharmacist, WD CHCP	NHS	
Penny Inglis	Senior Clinical Pharmacist	NHS	
Wendy Jack	Joint Strategy & Planning Manager	West Dunbartonshire Council	
Jim McKay	Chair	Focus	
Maureen McLellan	Member	Focus	
Les McQueen	Senior L&E Advisor	NHS	To December 2010
Nuzhat Mirza	Corporate Inequalities Support Practitioner	NHS	
Shelagh Palmer	Health Coordinator	Visibility	
Susan Taylor	Learning Disability Nurse	West Dunbartonshire Council	
William Wilkie	Lead Optometrist, WD CHCP	NHS	

Visual Impairment Resource Development Group

NHS
Greater Glasgow
and Clyde

Aim

More specific aims
– the outcomes we
want to see

What we need to do to enable us
to achieve our planned outcome
– our outputs

Visual Impairment Resource Development Group

Our aim:
To explore the medication-related communication difficulties experienced by patients with an emphasis on those with a visual impairment, including those with learning disabilities, and to support and advise healthcare professionals working with this group to improve the services they provide.

The outcomes we want to achieve:
1. The availability of a resource pack of hints and tips for pharmacists and other Healthcare professionals to use that gives useful information on ways of storing/identifying and labelling medicines that enables good compliance.
2. Use of this resource by community and hospital Pharmacists and accessible to all other healthcare professionals across NHSGG&C
3. Following the WD pilot using the resource, plan to roll out across NHS Greater Glasgow and Clyde.

   (Also possibilities of then rolling out across NHS Scotland via NES)

The activities / outputs that will enable this:
A. Undertaking a scoping exercise better to understand what is currently available and the current ways that people may identify and label medicines
B. Undertaking a brief gap analysis to identify unmet need for specific resources
C. Obtaining resources from external sources as appropriate
D. Developing resources as needed
E. Devising a communication plan for the project
F. Devising an evaluation strategy for the project
G. Developing supporting materials for training and education

Visual Impairment Resource Development Group

Action plan

Visual Impairment Resource Development June 2010

Activity (sub-group)	Contributing to Outcome(s)	Lead	Other main contributors	Actions	Timescale	Progress
Gap Analysis (B)	1	MB	FOCUS, Visibility Scotland PT, MB	Set up focus group of people with an emphasis on visual impairment +/- learning disability to identify unmet need with regard to medicine-related communication.	by 31/8/10	
Identify currently available aids/ good practice (A,C)	1	LMcQ	LMcQ, MD, WW, PI, PT, FOCUS, Visibility Scotland	To obtain &collate examples of good practice from community pharmacy, hospital setting, community optometry, NHS, voluntary and commercial sources to help inform the contents of the pack	by 31/8/10	
Develop resource pack (D)	1	LMcQ	?	Devise content, layout and alternative formats of resource. Obtain funding & organise production.	by 28/2/11	
Devise a communication plan for the launch of the resource (E)	2	PT		Identify target group (health professionals) within West Dun who would use this resource. Identify best communication methods. Organise funding for any resources required. Identify how to "advertise" to patients.	by 1/4/11	

Developing supporting materials for training and education (D,G)	1,2,3			Identify availability and appropriateness of current training materials.	by 28/2/11	
Devise an evaluation strategy for the project (F)	1,2,3	?	PT, FOCUS, Visibility Scotland LMcQ	Baseline assessment of knowledge of CPs? Then a follow up assessment of knowledge ? months later, ? Assessment of frequency of use of the resource. Assessment of impact of resource on the targeted end user group	by 28/2/11	

PT - West Dun Prescribing Team

West Dunbartonshire CHCP

Visual Impairment Resource Development

Gap Analysis group – narrative of the process

Aim of group:

- It was agreed that the purpose of the gap group was to assess unmet need with regard to medicine-related communication with an emphasis on visual impairment +/- learning disability

Group membership:

- Margaret Black – CGSU, patient involvement
- Shelagh Palmer – Visibility, Health Co-ordinator
- Wendy Jack - West Dunbartonshire Community Health and Care Partnership, Strategy Manager
- Susan Taylor - Learning Disability Services, Community Learning Disability Nurse
- Julie McCormack - Learning Disability Services, Total Communication Support Worker

Work undertaken:

- Group members met three times and following each meeting an e-mail note of the discussion was circulated to all group members.
- Tasks were discussed and agreed, and summarised on workplans, which were updated to reflect progress and changes to plans resulting from practical limitations.
- Between meetings, members were in touch by e-mail and telephone to agree interview schedules etc.
- The findings of the group were summarised in a brief report (Appendix 6)

What worked well:

- Having representation on the group from NHS, local authority and the voluntary sector, and the range of knowledge and experience group members contributed
- Having a face to face meeting to initiate the work of the group and then being able to maintain contact through e-mail and a small number only of follow-up meetings
- Advice and support received from staff (both NHS and Visibility) at Gartnavel General Eye Department – enabled by pre-existing connections

Challenges encountered:

- Time pressures faced by group members
- Identification of appropriate locations / services / databases at / through which to meet people within the target population

Suggestions / recommendations:

This group worked well and was able to fulfil its remit. In setting up a similar group in the future, it would be of value to discuss potential time requirements to ensure all group members are able fully to participate in the work of the group.

MB May 2011

West Dunbartonshire CHCP

Visual Impairment Resource Development

Gap Analysis group

Work undertaken:

- Attendance at Gartnavel clinics and discussion with attendees.
- Attendance at Focus meeting
- Focus groups with people with learning disabilities
- Liaison with talking newspapers

Outcomes:

Proven difficult to find people who are on regular medications, and have significant sight loss, and have problems in taking meds that are not overcome through help from others.

Main concerns / points are:

Not sticking labels over Braille
Having labels that effectively obscure printing on box so aiding legibility
Using elastic bands and tearing boxes
Keeping meds on same shelf of cabinet
Asking pharmacist to explain packaging of eye drops
Pharmacists being alert to changes in packaging / format
Pharmacists being able to explain how different dosette boxes work and having different sizes / styles to offer

Importance of liaising with pharmacy industry to encourage them to adopt industry wide standards
Importance of checking with person that they are able to differentiate between packs
Importance of liaising with carers and support workers
Being aware that a carer may have a VI

Suggestions / recommendations:

Provide this information to ward staff etc – upskill those ward staff and help people as they are being discharged on medications for first time.
Provide this information to hospital pharmacies, supermarket and health centre pharmacies, not just community pharmacies

MB March 2011