

## Appendix 2- Service User Involvement – It's Impact

### Pregabalin and Gabapentin

Through his engagement with Service Users, a Service User Representative spotted a theme about Pregabalin & Gabapentin medications. He heard they were causing our Service Users significant problems and witnessed individuals approaching our service in desperate need of support. He spoke to staff and discovered that for clinical reasons, our service was not in a position to prescribe them.

He knew very little about Pregabalin and Gabapentin himself and wanted to do some research. As a Service User Representative he has access to our computer system and used this to investigate the issue online, as well as explore our internal policies and procedures. His research taught him that the medications were originally developed to treat epilepsy, however, are now commonly being used to treat conditions like neuropathic pain and anxiety. He also discovered that:

- it's possible to become physically dependent on them
- at the point of stopping the medications, if doses are not reduced gradually, the patient can experience significant withdrawal symptoms
- they carry an acute overdose risk, especially when used with opiates
- deaths related to these medications are rising year on year
- the British Medical Association were backing calls to make Pregabalin a "Class C" drug

He was really concerned about what he learned as it became clear that these medications pose a serious risk to our Service Users, especially those who use illicit or prescribed opiate based substances. His concern was further reinforced by the fact that he found no evidence of a formal CGL policy regarding Pregabalin and Gabapentin use.

He shared his new found knowledge with his fellow volunteers who became equally worried for our Service Users and as a team, decided to gauge the prevalence of Pregabalin and Gabapentin use amongst our Service Users via a targeted survey.

Within a few days, the team identified 42 Service Users who were using the medications. Worrying headlines from the survey result showed that of the participants:

- 50% were obtaining them illicitly (not prescribed)
- 47% were also using methadone and heroin
- 21% were also using methadone, heroin and alcohol

The Service User Representative was supported to turn his research into an evidenced based report which made some recommendations to CGL, which if undertaken, would improve the support available to our Service Users on a national scale. The recommendations include the development of a:

- training to upskill and educate staff
- clear harm reduction message for Service Users
- central CGL policy and procedure
- official communication to our partners e.g. GPs, Prisons etc. highlighting the risks of dependency, withdrawal and overdose
- detoxification prescribing option

The Service User Representative presented the report at a Midlands Regional Service User Council, a group who meet on a monthly basis to share learning and escalate Service User feedback. Walsall, Dudley and Nottinghamshire services were present and as well as showing their support for the

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report's recommendations, they also shared accounts of how Service Users in their own towns and counties were being affected.

The Regional Council escalated the report to CGL's Medicines Management Board and as a result Prun Bijral, CGL's Medical Director, contacted the Service User Representative and his fellow volunteers. He advised them he had read the report and its recommendations and agreed that CGL could do more in relation to Service User safety and Pregabalin and Gabapentin use.

Since then a 'working group' has been created, which is led by our Service User Representatives and supported by Mohammed Fessal (CGL's Chief Pharmacist). Its main focus is to turn the report's recommendations into a reality which includes plans to conduct a clinical study on the issue, in partnership with the University of Manchester. Birmingham's Service User Representatives have developed a harm reduction leaflet that is aimed towards Service Users and will help people understand the risks of using Pregabalin and Gabapentin so they can make safer and more informed choices.

If the planned clinical study is a success, it would put CGL in a stronger position to conduct Pregabalin or Gabapentin detoxifications in the future. The working group are currently developing a 'prevalence study' that will assess the level of need that exists in Birmingham, plus three other West Midlands based CGL services and the Service User Involvement teams within each of those services, will be integral to this piece of work.

### Service User Planning

Trevor Bedford who works within our Quality Improvement Team in Birmingham, approached our Service User Involvement Lead to ask if our team of Service User Representatives could review CGL's paper version of its Service User Plan, which workers and Service Users together in 1-2-1 appointments. The purpose of the plan is to help Service Users plan for their recovery by setting relevant and achievable goals.

Our Service User Representatives reviewed the document and came to the following observations:

- it was too overwhelming i.e. there were approximately 50 questions to answer within the plan, which they felt would be too much for Service Users to consider in one go
- the language that was used in the form was not 'service user friendly' i.e. it used 'service jargon' that Service Users may not understand
- the format of the form was not fit for purpose i.e. there was not enough room for the Service User to record information that was important in their recoveries
- the form looked like "just another form" and because of this they felt that it wouldn't feel important or helpful to Service Users, when setting their recovery goals

Our Service User Representatives made the following recommendations:

- they strongly felt that before the planning stage, the significance of the Service User Plan and how it will benefit them needed to be explained to the Service User – in very simple terms. And that within this discussion the service would need to convey/discuss how it's the Service User's plan and their responsibility i.e. they "own it"
- they felt it's important to acknowledge why they drink/use drugs but ultimately the main focus should be on what they "need" and want to "achieve" in their lives i.e. the plan cannot just be based around their drug/alcohol use, but also around their life goals/aims

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- they felt individuals should have lots of “options” available to them – not just a prescription or a detox
- in order to cut down on the overwhelming amount of questions, they felt a simple scaling exercise would support the Service User to consider and choose their priorities
- they also felt like the plan needs space for them to record their successes – no matter how big or small, so Service Users can reflect on their achievements.

The group of Service User Representatives went on to design their own version of a Service User plan, ensuring that all of their recommendations and observations were incorporated within its design.

### **What's happened as a result of their feedback?**

The Quality Team shared the feedback and the Service User Representative's version of the plan with Senior Management.

The Senior Management team endorsed the new plan and agreed that a set of 'service wide' workshops should take place, to share the new plan with all frontline staff and the reasons behind its design.

These workshops have since taken place and were attended by the Service User Representatives that designed the new plan.

Their work was well received by frontline staff who are now encouraged to use the new planning intervention with their Service Users, instead of the old version that was designed by the service.