

COMPLAINANT v JAZZ PHARMACEUTICALS UK

Allegation about disclosure of company involvement

CASE SUMMARY

This case was in relation to a declaration of funding provided by Jazz to a patient organisation. Funding was provided by Jazz for the review and production of an educational support guide for families. The complainant alleged that the declaration of funding was not provided at the outset of the guide.

The outcome under the 2021 Code was:

Breach of Clauses 23.2 and 25.3	Failing to ensure that all sponsorship is clearly acknowledged from the outset (Panel made one ruling which applied to both Clauses)
No Breach of Clause 2	Requirement that activities or materials must not bring discredit upon, or reduce confidence in, the pharmaceutical industry
No Breach of Clause 5.1	Requirement to maintain high standards at all times

**This summary is not intended to be read in isolation.
For full details, please see the full case report below.**

FULL CASE REPORT

A complaint was received from an anonymous, contactable complainant who described themselves as a health professional about Jazz Pharmaceuticals UK.

COMPLAINT

The complaint wording is reproduced below with some typographical errors corrected:

“Family guide booklet by [named patient organisation] has been developed by educational grant from Jazz Pharmaceuticals. The Jazz educational grant declaration was not provided at outset but only at end of the booklet. Patients need transparency from outset of company involvement. Guide is [URL provided] Breaches of clauses 23.2, 25.3, 5.1, 2.”

When writing to Jazz, the PMCPA asked it to consider the requirements of Clauses 25.3, 23.2, 5.1 and 2 of the 2021 Code.

JAZZ'S RESPONSE

The response from Jazz is reproduced below:

"Thank you for your letter of 28 May, in which you notified us of a complaint from an anonymous HCP, relating to the positioning of the company transparency statement on a [named patient organisation] charity booklet, developed as a support guide for Families of people with [medical condition]. We were requested to respond to this matter with consideration to the Clause requirements of 25.3, 23.2, 5.1 and 2, as cited by the complainant. The complainant's stated concern is that 'Patients need transparency from the outset of company involvement' and the complainant writes that the 'Jazz educational grant declaration was not provided at the outset but only at the end of the booklet.' As you see later, this statement is factually incorrect.

The complainant did not provide the 'booklet' directly as evidence but rather provided a weblink. The weblink shared with us in the complaint is the direct link to a pdf document entitled 'Family Guide', consisting of 49 double-view pages, which was available to readers by download on the [named patient organisation] charity website. We observed that for a reader to get to the booklet from the landing page of the charity website they need to navigate through at least 4 website pages. The detailed and engaging content of these pages illustrate the dedication and importance of the work undertaken by [named patient organisation] in their quest to support families and people living with [medical condition].

The ABPI strategy includes making sure patient engagement is consistently at the heart of our industry's work, with a range of commitments including 'making collaboration between industry and patient organisations easier' and to 'Foster a patient centred organisational culture at the ABPI while supporting our industry members to do the same'. At Jazz our vision is to make a positive impact in the lives of the patients and families we serve; this is aligned to the principles-based approach set out in the ABPI Code. We build ethical relationships with stakeholders, act with integrity and are transparent in our interactions. We value the importance of independent decision-making by all those we interact with.

We have conducted a thorough investigation into the matters alleged in this complaint which required us to notified [named patient organisation] that we are in receipt of a complaint related to their booklet (Enc. 1).

GW (now Jazz) was approached by [named patient organisation] in 2019 with a request to provide funding in support of their planned patient activities (Enc. 2) for 2020. Jazz agreed to give £15,000 through an unrestricted grant in January 2020 (Enc. 3). As the difficulties of the pandemic began to unfold, [named patient organisation] approached us again to ask if we were able to increase our original funding amount, and an additional £30,000 unrestricted grant was agreed in June 2020 (Enc. 4).

The complainant alleges a breach of clause 23.2 and writes that 'The Jazz educational grant declaration was not provided at the outset but only at the end of the booklet'; this

statement by the complainant is factually incorrect since the Jazz grant declaration statement is provided both on the Contents page and on the back page of the booklet. Whilst the complainant asserts that 'Patients need transparency from the outset of company involvement', Clause 23.2 requires that '*Company involvement should be made clear for donations and grants to the extent possible.*' Jazz gave written instructions to [named patient organisation] that the materials should contain a declaration, at the beginning of the booklet and at the back of the booklet, that the booklet had been funded by an educational grant from Jazz (Enc. 5). The booklet does contain a clear declaration on the contents page, before any of the substantive information in the booklet is shared, and again on the back cover. We believe this fulfills the requirements of clause 23.2 of the Code that '*Company involvement should be made clear for donations and grants to the extent possible.*'

During our investigation we learned from [named patient organisation] that introductory pages were added for the purposes of explaining to the reader the role of [named patient organisation] and the purpose of the Family guide rather than starting directly with the contents listing page, meaning that the Jazz company declaration statement appeared in a clear space at the bottom of the contents page. As it is at the bottom of the contents page, the financial support from Jazz is displayed and is clearly declared before the reader engages with the content pages of the booklet. As the preceding pages are background information on the patient organisation, which is independent from Jazz, to place the Jazz declaration on these pages may give the reader a misleading impression of Jazz involvement with the patient organisation. Jazz did provide guidance about the appropriate wording declaring our involvement in the publication and the positioning of that wording. That guidance has been carried out by [named patient organisation] to the extent possible, given that this was an unrestricted educational grant with strict arm's length arrangement. We therefore refute the allegation of a breach of clause 23.2.

The complainant alleges a breach of clause 25.3 but does not provide an explanation for this allegation nor which aspect of the Family Guide booklet has caused them to allege this clause. The funding provided to [named patient organisation] to support the booklet development was provided through an unrestricted educational grant and not through a sponsorship, as acknowledged by complainant 'The Jazz educational grant declaration...'. The guidance issued by the PMCPA to support the 2021 Code changes, makes clear the distinctions between Donations and Grants from Sponsorship and Support (Enc. 6 & 7); the provision of funding to [named patient organisation] cannot be both a grant and a sponsorship. Jazz involvement was through a grant and not a sponsorship. Clause 25.3 therefore does not apply to this grant and accordingly we refute the allegation of a breach of clause 25.3.

The complainant alleges a breach of clause 5.1 in relation to the Jazz educational grant declaration statement on the [named patient organisation] Family Guide. As presented above, in our response to the allegations of clause 23.2 and 25.3 breaches, we maintain that we responded appropriately to the funding request from [named patient organisation] and have demonstrated high standards in our interactions and that the company declaration has been made clear to the extent possible. We refute the allegation of a breach of Clause 5.1.

The complainant alleges a Clause 2 breach in relation to the Jazz educational grant declaration statement on the [named patient organisation] Family Guide. Clause 2 is a sign of particular censure and is reserved for such circumstances, we believe that our interaction with [named patient organisation] in providing this funding support is a legitimate one, has been conducted throughout to Code Principles and high standards and therefore we refute a breach of Clause 2.

At Jazz, we take our commitment to upholding industry standards through our activities and interactions seriously, and I hope that the information provided will lead to resolution of the allegations made in this case.”

PANEL RULING

This case relates to a declaration of funding provided by Jazz to a patient organisation. The funding, provided as a grant, related to the review and production of an educational support guide for families of people with a particular medical condition. The complainant alleged that the declaration was not provided at the outset of the guide.

Jazz submitted that they were approached by the patient organisation in 2019 to provide funding in support of planned activities for 2020. Jazz provided an initial amount of £15,000 through an unrestricted grant in January 2020 for the purpose of undertaking a review and updating existing educational materials. Following the start of the Covid-19 pandemic, Jazz were approached for an increase in the initial amount, and an additional amount of £30,000 was provided to the patient organisation in June 2020.

The document entitled “Family Guide” consisted of 49 double view pages. The guide was downloadable as a pdf on the patient organisation’s website although was designed primarily as a hard copy booklet as a resource for caregivers. On publication, the declaration of Jazz’s involvement appeared on pages 5 and 49 of the guide. The first 5 pages of the guide included the following information:

Page 1 (Cover Page) – included a large image of a family. The patient organisation logo appeared in the top right corner and the title of the guide appeared below the image.

Page 2 (Welcome Page) – included largely text in two columns with an image of a young child interspersed between the text. The text set out who the booklet was for, and a brief overview of the information within it. In small font at the bottom of the second column was a note setting out who compiled the guide.

Page 3 (About Page) – included text about the organisation including how it began, what they did and a list of names and job roles of its Medical Advisory Board.

Pages 4-5 (Contents Page) – was split into four parts. At the bottom of page 5 after all of the content had been listed appeared the wording “Supported by an educational grant

from Jazz Pharmaceuticals". This appeared in small font beneath version control and above a copyright statement.

A second declaration of Jazz's involvement appeared on the back cover using similar wording.

The Panel was provided with a copy of the grant agreements for both grant payments. Both agreements contained the same wording at paragraph 4.1 which stated,

"Where requested by the Funder, the Recipient shall acknowledge the Funder as the source of the Grant. The Recipient shall not publish any material referring to the Funder without the prior written agreement of the Funder."

There was no further detail in the contracts as to the wording of the declaration or what prominence it should be given.

The Panel was provided with a copy of an email exchange between Jazz and the patient organisation in which they discussed the wording and location of the declaration of support in the guide. The patient organisation confirmed that the declaration wording would appear on the back cover and inside the front cover. Jazz subsequently confirmed the wording "Supported by an educational grant from GW Pharma Limited (now part of Jazz Pharmaceuticals)" and indicated confirmation of the location.

Jazz in their response, submitted that during their investigation into the complaint they had learned from the patient organisation that the introductory pages two and three were added for the purposes of explaining to the reader the role of the patient organisation and purpose of the guide rather than starting with the contents page. This meant that rather than appearing inside the front cover of the guide, the declaration appeared on page five. The Panel made no ruling on whether a declaration on the inside front cover would have been acceptable.

The Panel noted Jazz's submission that the provision of funding to the patient organisation cannot be both a grant and a sponsorship. The Panel bore in mind the broad definition of sponsorship at Clause 1.22 and the definition of donations and grants at Clause 1.5 and considered that the terms were not mutually exclusive. The Panel considered it plain from the wording of the definitions that funding could be both sponsorship and a grant.

Clause 25.3 stated that "Companies must ensure that all sponsorship is clearly acknowledged from the outset. The wording of the declaration of sponsorship must be unambiguous and accurately reflect the extent of the company's involvement and influence over the material." The Panel considered that Clause 25.3 applied to all forms of sponsorship arrangements in place and was not limited in its application, reflecting the broad definition of sponsorship in Clause 1.22. The Panel accepted that this was a grant but that did not preclude it from falling within the broad definition of sponsorship to which Clause 25 applied. Its intention, in line with the spirit of the Code, was to ensure transparency in declaring a company's involvement. It also closely mirrored the requirements of Clause 23 which related specifically to grants.

The Panel considered the location of the declaration and whether it was at the outset of the guide as required by Clause 25.3. Jazz submitted that the declaration appeared before the reader engaged with the content of the guide. The Panel considered that the information which appeared on pages two and three of the guide was part of the content. The two pages were largely text and comprised information including who had contributed to the production of the

guide. The Panel considered that page two was intended to be a welcome page and made reference to those involved in compiling the guide. It also referred to “the first section About [medical condition]” as a “helpful introduction” suggesting that this was part of the content of the guide. The ‘About’ section on page three included a thank you to “fundraisers and donors” as well as a list of names and qualifications of Advisory Board members who assisted in the production. The contents at pages four and five were split under four colourful headings with a picture appearing next to each section. The location of the declaration at the bottom of page five in a smaller font than the rest of the content list did not give it any prominence and the Panel were of the view that a reader could have missed the declaration entirely. In this regard the Panel noted that the complainant only referred to the declaration on the outside back cover.

The Panel considered that a declaration of involvement on the bottom of page five of the material was inadequate and failed to satisfy the requirements of Clause 25.3 that the sponsorship should be clearly acknowledged from the outset. A **breach of Clause 25.3** was ruled.

The Panel noted the relevant requirements of Clause 23.2 that ‘company involvement should be made clear for donations and grants to the extent possible’ and bearing in mind its ruling above in relation to Clause 25.3 it followed that the declaration of involvement did not meet the requirements of **Clause 23.2 and ruled a breach** accordingly. The Panel noted the similarities in the requirements for the declaration under Clauses 25.3 and 23.2 and treated the allegation on this point as one matter.

Although no specific allegation was raised in relation to the written grant agreement, the Panel was concerned that the agreement did not set out requirements for the location or wording of the declaration of involvement, in accordance with the Code. However, on balance the Panel considered that the agreement did include reference to a requirement of a declaration and in that regard, the Panel did not consider that Jazz had failed to maintain high standards. The Panel ruled **no breach of Clause 5.1**.

The Panel did not consider that the particular circumstances of this case warranted a breach of Clause 2 which was reserved to indicate a particular censure; **no breach of Clause 2** was ruled.

Complaint received 16 May 2024

Case completed 20 June 2025